DOCUMENT RESUME

ED 333 709 EC 300 477

TITLE The Common Pursuit: Improving the Quality of Life for Illinois Citizens with Disabilities: Implications for Restructuring the Planning and Management of State Services.

INSTITUTION Illinois Planning Council on Developmental Disabilities, Springfield.

PUB DATE Feb 91

NOTE 81p.

PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC04 Plus Postage.

DESCRIPTORS Administration; *Agency Cooperation; Community Programs; *Delivery Systems; *Disabilities; Government Role; Human Services; *Long Range Planning; Needs Assessment; Quality of Life; Staff Development; State Government; State Legislation; *State Programs; Values

IDENTIFIERS *Illinois; *Strategic Planning

ABSTRACT

The report presents 10 brief issue papers that focus on improving Illinois state planning and administrative functions for the ultimate purpose of improving conditions for Illinois citizens with disabilities. Common themes include more active involvement of the disabled themselves and their families in the planning, delivery, and evaluation of state services; the need for a coordinated interagency planning and implementation process; and an emphasis on people rather than programs. Each issue is examined in terms of a vision or goal, issue definition, background, issue analysis, a proposed new model, and recommendations. The following issues are addressed: (1) a common philosophical and value base for all state services and planning; (2) development of common interagency assessment strategies and functional categorization; (3) development of a common statewide information and data base; (4) development of common interagency geographic boundaries; (5) a single interagency consumer-based planning and advisory body with subgroups for each state agency; (6) avoidance/alleviation of duplication of services; (7) coordination of staff development and training among state and community agencies providing services; (8) development of a common interagency life-span case coordination system; (9) development of state office complexes at the community level; and (10) development of significant legislation to implement the interagency strategic plan and other interagency relationships. (DB)

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# THE COMMON PURSUIT

## Improving the Quality of Life for Illinois Citizens with Disabilities: Implications for Restructuring the Planning and Management of State Services

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Illinois Planning Council on Developmental Disabilities
February, 1991

John T. Porter
Chairperson

Cathy Ficker Terrill
Director

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## INTRODUCTION

The Illinois Planning Council on Developmental Disabilities believes it is imperative to reexamine how the state administers services for persons with disabilities. The Council has chosen to focus its examination on key issues involving the planning and administration of services for persons with disabilities generally, rather than for persons with developmental disabilities specifically. It is the Council's position that the issues impacting upon persons across all disabilities are comparable, if not identical, to those issues surrounding the specific needs of persons with developmental disabilities. Because of its unique function in state government as a planning agency and because the Council does not provide direct services to individuals, the Council is in a position to fairly and independently examine the service system without a conflict of interest. For this examination, the eleven state agencies which are represented on the Council provide an important interagency perspective.

Although the series of eleven issue papers which are presented may appear to focus on recommendations for improving the planning and administrative functions of state government, this is actually only a means to an end. The true focus is the people behind the issues--specifically, the state's one million citizens with disabilities. Through the concepts presented in these papers, the Council proposes a new way of thinking about how state services can be more effectively planned and administered to improve the quality of life for Illinois citizens with disabilities and their families.

At first glance it may also be unclear why the Council has chosen to submit issue papers pertaining to the functions of planning and administration rather than addressing improvements needed in direct services such as housing, education, health and employment. The Council recognizes that there are many expert advisors and considerable documentation at the disposal of the Administration which can provide an assessment of direct services and recommendations for their improvement. What is often neglected is the realization that the provision of direct services can either be strengthened or weakened by the planning and administrative structures which are the underpinnings for those services. Without an effective planning and administrative structure to support direct services, even the most innovative service initiatives often falter. An effective planning and administrative structure provides a solid foundation on which direct services can be built.

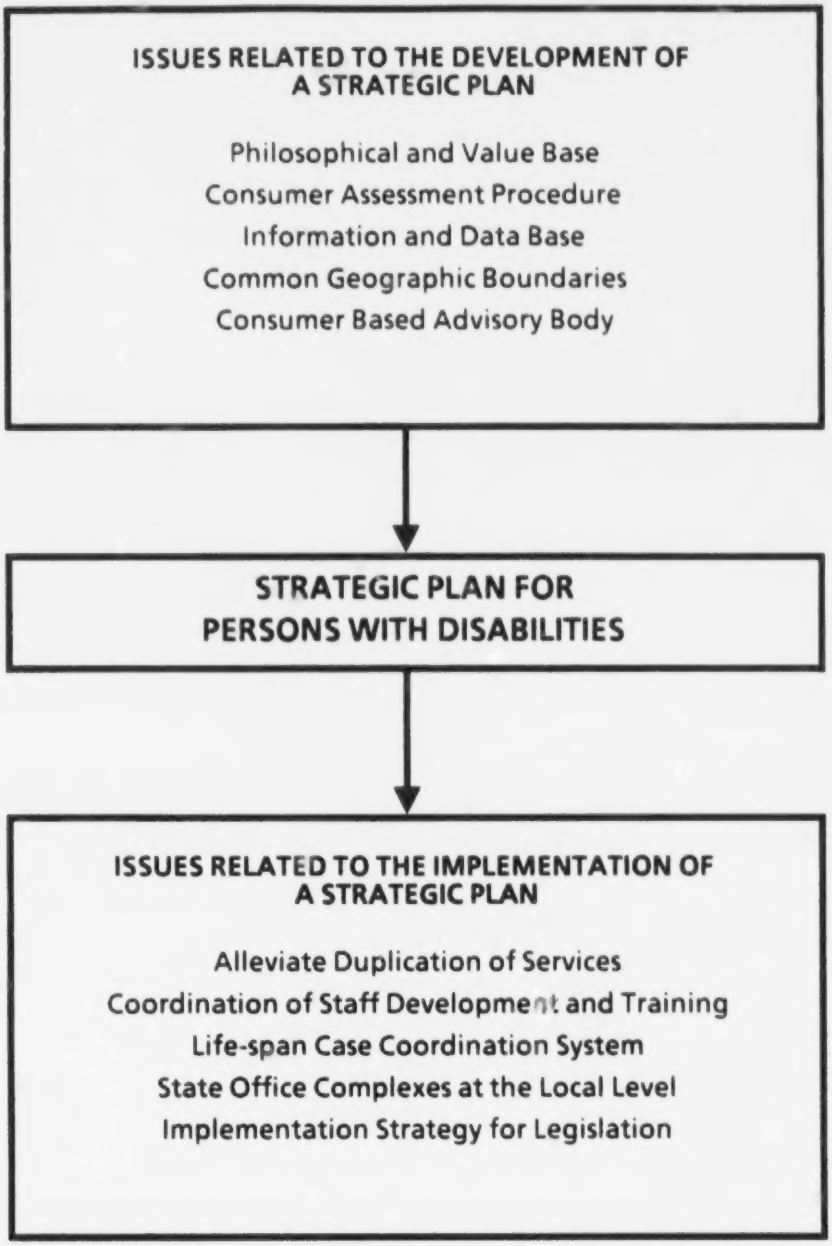
The purpose for examining these issues is to present a conceptual base for further discussion and investigation. The concept papers are not intended to be definitive

statements on the issues nor do they cover all possible structural aspects. Rather, the intent is to highlight new models for improving those selected areas which the Council believes warrant reexamination.

Throughout the papers several common themes are presented. First, and most importantly, is recognition that persons with disabilities and their families must be more actively involved in the planning, delivery and evaluation of state services. Second, all services should be planned and implemented through a structured, coordinated, interagency process which is guided by progressive social values toward persons with disabilities and implemented through principles which represent the best practices in service provision. And third, it is recognized that the frame of reference for each new model is people and not programs. By focusing on people with disabilities and their families, the purpose of public service will be reinforced, namely to serve citizens of the state, not to build separate and autonomous programs, agency by agency, into which people are expected to fit.

The papers present models to restructure planning and administrative functions in order to make informed decisions concerning the future service system and to improve the administrative support functions across state agencies. Emphasis is placed on the examination of planning and administrative functions which can be either consolidated or more effectively coordinated to improve direct service provision. The nucleus of the new model is the development of a Strategic Plan which would contain the Values, Visions, Trends and Issues which will guide the development of future service systems. As the following figure illustrates, the remaining issue papers present input or functional elements which are necessary precursors for interagency strategic planning and output or functional elements which will facilitate the implementation of the Interagency Strategic Plan.

The Council believes that it is an opportune time to explore a new way of thinking about the structure for the planning and administration of services for persons with disabilities. It is the Council's intent to serve as a catalyst for reexamining key structural issues and to provide a conceptual base for new models which can ultimately result in improving the quality of life for all Illinois citizens with disabilities and their families.


ISSUES RELATED TO THE DEVELOPMENT OF A STRATEGIC PLAN
Philosophical and Value Base
Consumer Assessment Procedure
Information and Data Base
Common Geographic Boundaries
Consumer Based Advisory Body
STRATEGIC PLAN FOR PERSONS WITH DISABILITIES
ISSUES RELATED TO THE IMPLEMENTATION OF A STRATEGIC PLAN
Alleviate Duplication of Services
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Life-span Case Coordination System
State Office Complexes at the Local Level
Implementation Strategy for Legislation

**ISSUE: THE NEED AND RATIONALE FOR DEVELOPING STRATEGIC PLANNING IN ILLINOIS FOR CITIZENS WITH DISABILITIES.**

## I. VISION

Persons with disabilities must fulfill their visions to be productive citizens who possess the same rights, responsibilities and opportunities to achieve personal goals as all other fellow citizens. The development of a Strategic Plan for Illinois Citizens with Disabilities will provide a new way of thinking about how citizens with disabilities, working alongside leaders in the public and private sectors, can shape the policies, services and support mechanisms they need to reach their vision for the future. In conjunction with a value base that governs all principles and decisions guiding the planning process, strategic planning can: educate the public on disability issues, build consensus, develop a long term shared vision, position state government to seize opportunities, shed new light on important issues, identify the most effective uses of resources, and provide a mechanism for public-private coordination and cooperation.

## II. ISSUE DEFINITION

Over a decade ago, authors Phyllis Magrab and Jerry Elder stated that "At present, the human service system is actually a number of separate systems, including health, education, welfare, rehabilitation, recreation, employment, and housing. However, none of these systems separately can solve the multiple problems of handicapped persons (sic) and, therefore, there is a need for cooperation, coordination, and collaboration among these subsystems." (**Planning for Services to Handicapped Persons**, 1979, p.2) The "three Cs" of cooperation, coordination and collaboration have been a topic of discussion and research for over twenty years. However, a successful planning model to achieve the "three Cs" has not yet emerged in Illinois.

## III. BACKGROUND

Problems with cooperation, coordination and collaboration in planning often begin at the federal level. In order to capture federal funds to implement major federal/state programs, each state agency is required to comply with very divergent planning and reporting requirements. Each compliance plan focuses on a single program, often ignoring the reality that human service programs cannot effectively function independently of one another, and thus should not be planned independently of one another.

Because of the extensive amount of time devoted to compliance planning, few resources remain to develop new ways of thinking about how planning can unite the public and private sectors to assist persons with disabilities in achieving their personal visions. Such planning reform would develop a proactive orientation, build wide public support and combine resources from the public and private sectors to address those strategic issues which are most important to persons with disabilities.

The problems associated with federal compliance planning are further exacerbated at the state level when human service agencies establish their programs and services on different stated or implied values and build separate, often incompatible data bases, definitions, and classification systems. Problems are further compounded when programs are implemented using disparate geographical boundaries.

Another significant barrier to effective strategic planning is the lack of recognition that planning for persons with disabilities should not be limited to the domain of human services. Strategic planning must be integrated into general state government and community planning. If people with disabilities are to achieve their vision for social integration, the new way of thinking about disability issues will recognize the importance of interagency planning. For example, affordable, accessible transportation has been identified by people with disabilities as a major barrier to full participation in community life. Overcoming transportation obstacles must involve coordinated efforts by the Illinois Department of Transportation, local transportation authorities, and the U. S. Department of Transportation as well as various human service agencies and community groups.

Currently, most state agencies develop some type of state plan or annual report to provide direction for each agency's operations. One mandate developed to support integrated state agency planning is the Illinois Welfare and Rehabilitation Service Planning Act (Illinois Revised Statute, Chapter 127). This Act mandates the eight state human service agencies to develop an annual Human Service Plan to describe program goals and objectives, delineate implementation plans for budget priorities, and discuss service trends, future directions, and critical policy and program questions. Although the intention of the mandate was commendable when developed, it is time to reexamine the Act in light of recent best practices in strategic planning. The following analysis indicates that the Human Service Plan will need to be revised if it is to be an effective format for operationalizing the proposed strategic plan.

## IV. ISSUE ANALYSIS

An analysis of the Human Service Plan indicates that this plan does not support current best practices in strategic planning for persons with disabilities. Although the guidelines for developing the Human Services Plan appears to support strategic planning, in practice it becomes evident that the plan, as currently developed, does not support best practices for strategic planning for the following reasons:

- The Plan focuses on problems and incremental remediation within each agency, not visions and proactive, interagency activities to effect major system change. Additionally, issues involving persons with disabilities may or may not be addressed in many of the plans and plan development is limited to only those eight human service agencies covered under the statute (out of more than 70 state agencies);

- Documents are developed as annual operating plans for each agency, with no emphasis on interagency issues or coordinated approaches. No overall umbrella of statewide, strategic issues exist to guide planning and resource allocation. A centralized planning team is not in place to integrate and monitor the planning process across all agencies or to measure effectiveness;

- Different data bases and classification systems are used by each agency, thus plans lack comparability. Disparate policy and program values and principles cause conflicts among programs. The plans are also generally too long, too technical, and not user friendly.

The current planning process results in the continued proliferation of an uncoordinated, fragmented service system. Although many state agencies have developed numerous programs to impact on strategic issues such as housing, employment, and health care, the programs have been implemented in a piecemeal fashion at best. New initiatives are formulated each year before any one strategic issue is ever resolved.

Since state agencies have been placed in a position of having to compete for resources through the budget process, they consequently tend to guard their boundaries and work from within their own territories. This process has promoted a system whereby each agency views services for persons with disabilities from its own particular program perspective. The unifying focus on the lives of people with disabilities is superseded by the separate emphasis on individual agency programs.

## V. PROPOSED NEW MODEL

The development of a Strategic Plan for Illinois' Citizens with Disabilities would provide a unified vision for state policies and programs. The design for the planning process and responsibility for monitoring all phases of the process should be implemented through a Governor's Planning Office with assistance from other planning entities such as the Illinois Planning Council on Developmental Disabilities. To solicit input from all state agencies, a development team should be convened which would include a lead planner from each state agency. This team would form the technical link between the Governor's Planning Office and state agency planning divisions.

The planning process would include activities that characterize the best practices of strategic planning, such as:

- Starting with a value base and developing a vision for the future for persons with disabilities;
- Maintaining a consumer reference as the basis for the plan, rather than focusing on agencies, programs or services;
- Sharing power and forming partnerships for collaborative decision making, negotiation and consensus building;
- Opening up the planning process to embrace many stakeholder groups, including: persons with all types of disabilities of all ages and their families, all appropriate state agencies, legislative staff, community service providers, community leaders, and representatives from schools, universities, business and industry, and consumer and professional associations among others.
- Shaping public policy through analyses of existing policies to assess support for stated values and visions; and
- Developing strategic thinking regarding managing planned social change and refocusing resources on systemic issues.

Using the authority of the Governor's Office and gaining the support of many public and private stakeholder groups, a framework to guide the strategic planning process must be developed. For example, the following six components constitute one framework for strategic planning:

1. VALUES: A social value perspective is intrinsic to disability planning. Organizations must formally state the values for which they advocate. All strategic plans, policies and programs should support the stated values.

2. VISIONS: A planning process which helps people envision and reach consensus about future outcomes provides opportunities to create political support for decisions that will change current practices. Developing a clear vision requires balancing strongly held traditions against the need for system change.

3. PRINCIPLES: Planning principles serve as benchmarks to guide and assess the planning process. Principles based on the best practices of planning theory, provide all participants with a common approach.

4. MODEL: A simple, yet all encompassing model serves as the overall design for visualizing disability planning.

5. DATA: Strategic planning decisions should be based on the best data and information available to provide the rational basis for deliberation and decision-making.

6. PROCESS: The strategic planning process can be defined as a structured system for organizing and coordinating the activities of all persons involved in planning activities. The procedural steps in the planning process provide linkages between conceptual planning steps and implementation steps.

The strategic plan would be developed on a cycle to coincide with the gubernatorial term. The plan would unify and mobilize state and private resources around three to five issues which are deemed to have the greatest significance for improving the quality of life for persons with disabilities. Issue analysis will include assessing the overall coordination of resources among all stakeholder groups that are needed for issue management. The analysis will also assess the impact of each issue on state agencies and develop strategies for implementation.

Budget development would be coordinated across all entities involved in implementation. An issue budget package would be developed and presented to the Governor and legislature to request allocations for individual state agencies according to their respective roles in the implementation process. This issue budget package would also detail the share from non-state sources brought to bear on an issue to demonstrate the public-private partnership.

Within state government, implementation would be guided through an issue management system. Through a coordinated,

interagency approach, each affected state agency (different agencies will be affected to different degrees according to each strategic issue) will develop implementation strategies (objectives) to be included in the Human Service Plan and other annual operating plans. One section of an agency's general operating plan would be devoted to implementation of the strategic issue(s). Additionally, all other external stakeholder groups who participated in the planning process (ie: corporations, provider agencies, United Way, universities, local governments, foundations, etc.) would be encouraged to incorporate implementation strategies within their organizational plans.

The Governor's Planning Office would manage issues through a master implementation plan, comprised of all operational objectives from the public and private sectors. During the implementation stage, the Planning Office would have two primary responsibilities: managing a system for ongoing coordination and overseeing an evaluation system to provide ongoing feedback on the effectiveness of implementation. Adjustments would be made when necessary.

This paper has presented the concept for developing a Strategic Plan for Illinois Citizens with Disabilities. The development and implementation of this concept would constitute a major change in the state's planning process. It would entail a new way of strategic thinking for planning which would impact on both the public and private sectors. The successful development of a strategic planning process would significantly improve the quality of life for Illinois citizens with disabilities by building a vision of the future and by coordinating resources to focus on those strategic issues fundamental to the fulfillment of that vision.

## VI. RECOMMENDATIONS FOR NEXT STEPS

Major steps for developing a strategic planning process as described in this paper will include:

1. Governor's Planning Office holds discussion meetings with Illinois Planning Council On Developmental Disabilities and other state agencies who must be involved in helping to plan the planning process.

2. Conduct a feasibility study and stakeholder analysis to assess the climate, resources, opportunities and constraints for developing a new statewide strategic planning process.

3. Initiate the planning process through an educative approach, incorporating all stakeholder groups in the beginning to help develop the process and to secure their support.

# ISSUES RELATED TO THE DEVELOPMENT OF A STRATEGIC PLAN

**ISSUE: A COMMON PHILOSOPHICAL AND VALUE BASE FOR ALL STATE SERVICES AND PLANNING.**

## I. VISION

Value-based planning is an innovative concept which is gaining increased attention in human services. Values can be defined as statements of intrinsic worth which are the basis for determining behavior and which set basic, ethical standards for evaluating actions. Once defined and embraced, values serve as the underpinnings for all policy and program decisions.

Our founding fathers knew it was important to state common values. It may be helpful to recall the basic values upon which our republic was founded: "We hold these truths to be self-evident, that all . . are created equal . . . endowed with certain unalienable rights . . . life, liberty, and the pursuit of happiness."

Following the example of our founding fathers, it is equally important for state government to clearly define and operationalize existing values. Unfortunately, many governmental units rarely define their values. Therefore, they often adopt policies and attempt to develop programs that fail because they are not consistent with the values of their consumers. Cynergistic value development ultimately contributes to a more responsive service system. Clearly defining values prior to developing policies and programs is central to ensure successful implementation, effectiveness and the integrity of government services.

## II. ISSUE DEFINITION

In an ideal state government administration, values that guide services for persons with disabilities would be commonly agreed upon and easily understood. Values must be representative of the visions and aspirations of the persons with disabilities whom governmental units are mandated to serve. Consequently, a participatory planning process which includes persons with disabilities and their families, community provider agencies, professional and provider associations, legislators and policymakers representing state agencies would facilitate the development of a common set of values.

Also, in a pluralistic society, it must be recognized that there will exist competing or divergent values. In a democracy, persons are encouraged to express their differences. After the values of the various groups are defined and understood, it subsequently becomes necessary to state those organizational values in a way that is reflective

of the majority position.

From this participatory process, government would obtain a consensus on those values which are most highly supported by the public. These commonly shared values would be embraced and guide decision making in the Executive Branch, including all affected state agencies. All policies and services, for which the state has jurisdiction, would be congruent with the state values.

## III. BACKGROUND

We do not live in an ideal world. There has yet to be developed a common set of values concerning persons with disabilities which guide interagency decision making. In some cases, ambiguity continues to prevail as to whether individual agencies have a set of values to guide their decisions, policies and services. There is no evidence of significant attempts to develop a participatory planning process which would incorporate persons with disabilities, community provider agencies, professional and provider organizations, legislators and state agency policymakers.

## IV. ISSUE ANALYSIS

It is important to recognize that values are not static, but change over time. The periodic reassessment of values ensures that they reflect the most progressive ideologies. There has been a significant shift in public policy from that which fostered segregation and dependency of persons with disabilities to policies which now emphasize the values of independence, productivity and integration. Values must emphasize that persons with disabilities are people first irrespective of their disabilities.

It is important to understand that values are a major determinant of policy decisions and resource allocation. It is critical that common values become the major determinants. If the Governor's Office and the relevant state agencies are part of the process of determining common values, then decision-making regarding policy and resource allocation at the agency level would reflect these common values. It is equally critical that such values are developed in concert with consumers and their families, state agencies, consumer associations, etc. This would promote statewide continuity of policies, services and supports provided persons with disabilities.

## V. PROPOSED NEW MODEL

It is important for the Administration to focus their

attention on examining and stating values which will serve as the foundation for the development of policies affecting the lives of persons with disabilities and their families. After a clear statement of values is made, there will be guidance for making major strategic choices. Before plans can be developed regarding programs and resource allocations, it is imperative that values are clearly stated and understood.

Effecting such a value-driven system will require the involvement of consumers and their families working in concert with relevant policymakers. Facilitating this cooperative interaction will require the establishment of a task force comprised of consumers and their families, community provider organizations, provider associations, state agency representatives, legislators and the Governors office. This task force would develop a common set of values which will guide all policies, services and supports affecting persons with disabilities in Illinois.

## VI. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate requiring the development of common values affecting policies, services and supports for persons with disabilities and their families. Convene a task force which is comprised of consumers and their families, community provider agencies, state agency representatives, legislators and the Governor's office. This task force will address the following issues:

   a. The recommendations developed by the Advisory Committee formed under Public Act 86-921.

   b. All existing and proposed state policy and programs would be assessed to determine their degree of congruence with the adopted values. This would include examination of federal and state laws, standards and regulations, as well as all current policies. Recommendations would be made to enhance those policies and programs which support the values and to develop strategies to revise or rescind those which are in conflict.

   This common set of values would be presented to the Governor and his cabinet for their consideration to guide policy and resource allocation. These common values would be adopted across all state agencies and monitored to ensure consistent policy implementation.

**ISSUE: A BASIS FOR THE DEVELOPMENT OF COMMON INTERAGENCY ASSESSMENT STRATEGIES AND FUNCTIONAL CATEGORIZATION**

I. VISION

The state of Illinois will establish a policy that will entitle all persons with disabilities to functional assessments which will support them in the same natural community environments, including school, home, work and recreation that are enjoyed by persons who are not disabled. The administration of all assessments will be based on a common interagency strategy which will determine resources, services and supports desired and required by individuals with disabilities in order to achieve and maintain optimal community integration. The same principles of integrated, functional and individualized assessment will apply to individuals from birth through adulthood regardless of the categorical funding source of the support network.

The purposes for conducting individual assessments in the least restrictive environments will be: a) to identify discrepancies in performance and resources between the person who is disabled and persons who are not disabled; b) to provide information to service providers and support networks to assist persons in defining and reaching their personal goals; c) to ensure programs/services are developed to reflect the needs/interests/preferences of the individual; d) to build supportive community environments for the individual; and, e) to measure the quality of individual program outcomes.

II. ISSUE DEFINITION

It is generally recognized by service providers that persons with disabilities have the same desires, dreams and aspirations as people without disabilities. Research and promising practices have demonstrated that all persons develop and thrive best in natural environments where they may learn to communicate and interact with the individuals who make up the mainstream of community life. Therefore, it is critical that the professionals who utilize and interpret assessment data have a full understanding of the philosophical tenets of independence, productivity and community integration for all persons with disabilities regardless of the severity of the disability. With this in mind, Illinois has yet to develop a coordinated interagency system that ensures the right of individuals to functional assessments in natural environments. Additionally, consistent value-based practices pertinent to the utilization and interpretation of assessment data has yet to be formulated.

III. BACKGROUND

State and federal licensing protocols have required comprehensive assessments for more than 20 years. Additionally, emerging accreditation standards also recognize the importance of comprehensive assessment in the development of services and supports for persons with disabilities. Traditional assessment approaches have tended to focus on the utilization of norm-referenced and criterion-referenced tests. Contemporary practice suggests that functional assessment data is critical to successful program design.

As Michael S. Chapman and James F. Gardner (Program Issues in Developmental Disabilities, 1989, 129-130) so eloquently explain:

> 'because norm-referenced and criterion-referenced tests continue to be widely used, understanding both their limitations and strengths is important.
>
> Norm-referenced (or standardized) tests are used to evaluate one individual's performance against other individuals who have also taken the test. An individual's performance can then be compared with the norm or average score. As the word standardized implies, this type of testing follows strict guidelines in the administration of the test. The resulting score is usually expressed in the form of an intelligence quotient (IQ) or social quotient (SQ). The score obtained from these tests provide diagnostic information about the person. **This is helpful in obtaining funding or determining eligibility for programs, however, it is not pertinent in developing meaningful goals and objectives.**
>
> Knowing that a person has an IQ of 30 does not provide information about what the person can or cannot do. In addition, this type of information is subject to misuse, especially when the score is used to limit an individual's opportunity for growth. Determining that an individual has an IQ score of 30, may assume that the individual has limited capabilities and potential. Therefore, opportunities may not be provided. As a result of these low expectations and diminished opportunities, the individual may perform at a lower level than that of which he or she may be capable. The initial belief is subsequently reinforced and future opportunities are denied.'

Criterion-referenced tests assess the skills and abilities of an individual without comparison to others. These assessments determine where along the developmental continuum the individual is functioning and indicates how the individual performs in specific developmental areas. The problem with criterion-referenced tests is that no one test provides sufficiently detailed information in all skill areas

that need to be assessed. Developmental assessments tend to measure an individual's current abilities against a detailed set of developmental milestones. The basic underlying principle of developmental assessment requires that a person must master each milestone in progressive order. Unfortunately, this tends to result in persons receiving prolonged training in more restrictive settings than they need in order to accomplish these milestones. As a result, persons with developmental disabilities are not provided the opportunity to progress beyond that developmental level to more meaningful experiences in the community.

The nature of assessments has changed in recent years to focus on a persons individualized needs within a current or planned integrated environment. In this context the individual's skills and abilities are assessed using criterion-referenced, performance-based measures and/or functional assessments (Manfredini and Smith, 1988). Functional assessments focus not only on the individual but on activities across all domains of that individual's life, regardless of age, including attending school, working, recreating and living in the community.

Functional assessments measure the discrepancy between the individual's strengths/abilities and the skills necessary to function independently. Furthermore, functional assessments presume the person's right to choose activities in the community alongside persons who are not disabled. This approach recognizes that people need a variety of experiences in order to make meaningful and informed choices, builds upon strengths, and alleviates or eliminates the discrepancies between current skills and necessary skills. Equally as important, this approach recognizes that individuals must receive ongoing supports provided in integrated settings of their choice.

## IV. ISSUE ANALYSIS

The current Illinois system inflicts a multitude of assessments upon an individual that not only are meaningless to the person's real life but also are uncoordinated, duplicative across state agencies and expensive in terms of time and money. Extensive time is taken in assessing and reassessing a person when he/she could be receiving services and supports. Each time an assessment is conducted, there are costs to the person, the person's family, the state, the service providing agency, etc. Because so many assessments are required they often tend to provide duplicative information and can become regarded as "just another piece of paper." Finally, a major portion of the information is not transferred between service settings and must be duplicated each time an individual moves or transitions to another setting, adding to this wasteful use of already limited

resources.

Functional assessment provides a solid foundation for transdisciplinary team decisions which ultimately lead to the formulation of an effective individualized service plan. Assessments enable the team to clearly understand the persons strengths, needs, likes, dislikes and interests. Objective functional assessment data promotes the provision of optimal services and supports.

As long as persons with disabilities are not provided with functional assessment through coordinated state agency strategies, proof of program eligibility will continue to be the only meaningful outcome. Consequently, persons with disabilities will continue to be the recipients of inadequate services and diminished opportunities.

## V. PROPOSED NEW MODEL

All persons with disabilities will be entitled to receive functional assessments and subsequent supports and services necessary to attain and maintain a lifestyle equivalent to that of persons without disabilities. The state of Illinois will adopt a functional definition of disabilities through legislative and regulatory reform. All persons falling into that definition will be entitled, on a zero reject basis, to functional assessments within the community of their strengths, resources and needs. The primary focus of this assessment strategy will be to determine which services, supports and resources an individual needs, regardless of age, in order to attain and maintain a lifestyle equivalent to persons who are not disabled rather than merely determining program eligibility status. Assessment, services, funding and regulatory requirements will not inhibit a person's ability to choose where to live, where to work and where to spend leisure time.

Funding will be allocated according to an individual's choice of lifestyle rather than solely in accordance with the severity of the disability, type of facility or program. People with disabilities will not be required to sacrifice quality of life in order to receive the services, supports, and resources needed. Common values guiding state agencies will drive services that recognize that all persons with disabilities, regardless of severity, belong in integrated community settings. The amount and duration of support will vary from individual to individual and the necessity of long term support will not restrict a person's right to lead a productive life fully integrated into the community.

This new systemic approach will eliminate the need for labels such as "educable mentally handicapped, severe/profound, trainable, high functioning, low functioning, mild, moderate, quad, autistic, retarded."

Consequently, the preconceived limitations associated with such labeling and the resulting self-fulfilling philosophical implications would also be eliminated.

Assessments will occur in natural community environments encompassing all domains of the individual's life, regardless of age: education, home, work and recreation. All assessments will be based on the premise that persons with disabilities desire to be supported in the same environments enjoyed by persons who are not disabled. Services endemic to these environments would include: education, housing, mental health services, healthcare, legal supports, social services, transportation, employment and recreation. Information obtained through these functional assessments will be utilized within the transdisciplinary team process to determine specific discrepancies in individual skill levels and those resources/supports received by the individual. Additionally, through this discrepancy analysis, the process identifies those resources and supports necessary for maximum independent functioning. The process recognizes the importance of providing the individual the opportunity to experience a variety of options from which informed choices can be made. The determination of assessment and subsequent training/education/support environments will be made at the direction of the individual and/or designated significant others in instances where the individual requires assistance to make informed decisions. This approach would ensure the development of goals and objectives which would be clearly and measurably delineated in the individual's service plan. This service plan would be implemented through a cooperative interagency effort, regardless of funding, etc.

Assessments will be coordinated through an independent case management system and the assessment information will belong to the assessed individual, their family or guardian. The individual will use the information to obtain their choice of services, resources and supports.

## VI. RECOMMENDATIONS FOR NEXT STEPS

Obtain a governmental mandate to convene a group of representatives from state agencies, community organizations, advocates and consumers and their families to:

1. Develop and adopt a statewide value statement which recognizes that all persons with disabilities must have the same opportunities throughout their lives for happiness, fulfillment and personal achievement as do persons without disabilities. Furthermore, funds, services and supports must be provided to people with disabilities to enable and empower them and their families to achieve their goals in the least restrictive environments of their choice across all life domains: education, home, work and recreation.

2. Adopt a statewide functional definition of disability that includes references to all domains of an individual's life.

3. Adopt statewide policies and procedures for assessment strategies which entitle individuals with disabilities to appropriate meaningful value-based functional assessments.

4. Prepare an analysis identifying barriers within the state system and among state agencies in order to develop a blueprint for system improvements. This analysis would minimally address federal, state and local funding regulations, codes, policies, procedures and eligibility criteria. Additionally, this analysis would include the review of assessments being applied across all state agencies.

5. Develop an interagency strategic plan to remove barriers that have been identified as inconsistent with newly adopted values and assessment strategies. This plan must include all agencies providing services that impact on the major life domains of persons with disabilities.

6. In order to promote the newly adopted values, develop a system that provides initial and ongoing training and technical assistance to state agencies, regional personnel and community organizations through the unit on Staff Development and Training for Working with Persons with Disabilities (see Chapter IV. B. Coordination of Staff Development and Training Among State and Community Agencies Providing Services and Supports for Persons with Disabilities.)

**ISSUE: A BASIS FOR THE DEVELOPMENT OF A COMMON STATEWIDE INFORMATION AND DATA BASE.**

## I. VISION

A central information/data system for persons with disabilities will fulfill multiple functions, helping case managers, program planners, state agencies, legislators, and most importantly, the individual seeking assistance. This will be accomplished by a three part data system that first provides specific information at the individual level. The second part will aggregate individual data into a format that can be combined with the data of other participating agencies. The third part of the system will act as a unified information and referral source by listing the services and resources provided by these agencies. This system will provide information with an ease and accuracy not possible before. Individuals will benefit by better access to services, more efficient and effective resource allocations, and improved planning at all levels.

It should be stated that an ideal system starts from the needs of the target populations. Building such a system will require major revisions to the existing systems and the rebuilding of all data collection systems in the state. The thrust of this proposal is to work with the existing systems to the extent possible. Critical attention to the development of assessment data which stresses individual strengths versus individual deficits of persons with disabilities will be essential.

## II. ISSUE DEFINITION

The current agency data systems operate in almost total isolation from each other. Information not mandated or required for reimbursement may be difficult or impossible to obtain. Attempts to aggregate across departments are often futile. Efforts to coordinate resources are frustrated because of the difficulty in tracking individuals across programs and agencies. Different eligibility requirements and definitions have made it difficult for administrators or legislators to project the impact future populations may have on service systems. This results in duplication of services, improper services, or lack of services. Inadequate information exists for coordinated longitudinal planning and legislative efforts.

## III. BACKGROUND

The present information systems are developed to fulfill individual agency needs. Departments are required to collect

information in a specified manner for a variety of reasons including: reimbursement of services; federal, state, or local mandates; and internal management requirements. Definitions of eligibility, disability, services and reporting timeframes used within each agency are also developed in response to these forces. Besides different information requirements and definitions, departments vary in their ability and willingness to share information. This may be because of personnel and hardware limitations, confidentiality issues, internal policies or personal relationships.

Louis Rowitz, editor of **Mental Retardation**, argued for a national minimum data set for persons with disabilities for a number of years (1984, 1985, 1986). He equated the current system to a jigsaw puzzle with pieces missing. Most recently, Seltzer (1990) addressed the issue, suggesting that the Omnibus Budget Reconciliation Act of 1987 (OBRA) could be used as the mechanism for generating a unified data system for persons with disabilities. Several states including Missouri, Utah, Ohio and Michigan have undertaken this challenge with varying degrees of success. Within Illinois, a number of activities are currently underway to consolidate or share information, both within and between agencies. The Department of Mental Health and Developmental Disabilities is starting a three year federal grant to create a unified data collection system within the agency. Several agencies providing services to children are meeting to create a unified information system. The Departments of Rehabilitation Services, Mental Health and Developmental Disabilities and Public Aid have contracted with the University of Illinois at Champaign to collect a common data set for individuals involved in supported employment. These efforts are meeting the common problems of how to identify individuals, define services and service units, integrate incompatible data systems, define a common set of data elements, assess data integrity, assure confidentiality and overcome resistance from within the agencies and from service providers.

Costs associated with this project will vary immensely depending upon the number of agencies involved, the amount of information desired and the extent and type of change required. Agencies with systems that can produce the necessary data will incur the least cost. Agencies which do not have this capability will experience costs in proportion to the changes required.

The number of agencies included in this project will vary depending on the populations included (not only disability groups, but those who are thought to have significant impact on the person with the disability). The widest view will include every agency an individual and his/her family may contact prior to birth and throughout the person's life span.

Within an agency, this system will impact all levels involved in data collection, from the individual field representative to the top management.

## IV. ISSUE ANALYSIS

The results of the current system are well summarized by the statement used by Rowitz above. "Information is missing." Not only is information missing within an agency, but there is an almost total inability to combine data across departments. Decisions affecting resource allocations are frequently made without adequate knowledge of their effects on the populations involved. Additionally, future effects on the target population by other population segments, or even the results of past efforts are rarely considered.

This lack of information, at all levels of decision making, has had a significant detrimental impact on the lives of individuals with disabilities. Critical resources are sometimes misdirected, frequently dictated, often difficult to obtain and not readily apparent. This causes inefficiency in a climate where resources are becoming increasingly limited while needs are ever-increasing.

## V. NEW PROPOSED MODEL

The unified information system for individuals with disabilities depicted in Figure 1 is both simple in concept and beneficial to its participants. It is divided into three parts: individual information, aggregated data, and services/programs currently available. The individual information system will contain demographic information and a brief history of the programs and services in which the individual has participated. Individual identification is accomplished by a unique number, assigned when an individual first receives services. The information in this section of the data bank will be most useful to the service provider in determining individual history. Much of the information needed in this section is currently collected by agencies and would require little modification other than entry into the central system. Confidentiality and access issues will be addressed by a release document signed at the time of entry into a program. This section assures that individuals can be tracked across services and agencies.

The second part of the unified system will provide the participating agencies with data sets describing services activities in an increasingly aggregated format. At the base of the pyramid in Figure 1, information is collected at the individual level, identified by both the system and agency identification numbers. This information is used by the agency to provide services for an individual. This is the

area that could cause the greatest roadblock to implementing a central system, as any change will require altering existing data collection systems.

In this part of the system, increasingly aggregated reports are submitted to different management levels within each agency. These reports detail the service activities of the units below that level and can contain information in addition to the minimum data set established for section one. At the top of the pyramid, a data report is submitted to the central data bank, containing the information required by the minimum data set in a specific format. This data will be merged with information provided by other agencies, resulting in an aggregated data set available to all. The information included in this set is currently impossible to obtain. Once established, such information will allow decision-makers the ability to project future needs with accuracy.

The third section of the unified system will contain listings and descriptions of programs and services currently available inclusive of generic community-based services. Entries are made by the project or section managers responsible for the program via the same mechanism used in section one. The listing of programs and services available through this component of the system will acquaint an individual with the array of programs and services inclusive of generic community-based services currently available within the state.

The content of each section in the centralized system and implementation issues will be addressed by an interagency data committee. The composition of this committee will be critical. The members must understand the data systems within their agency. Additionally, they must have sufficient knowledge regarding programs within their agency to make decisions about what information is needed and what information could be omitted. These individuals must have sufficient support within their agency to carry out changes needed to comply with the data requirements of the unified system.

Within each agency, it is anticipated that the process of reviewing data collection systems may be problematic, but beneficial. Evaluating procedures and data for inclusion in the unified system will result in a more efficient system. The system will fulfill the current reporting requirements, and will also generate aggregated data on services and activities not currently available to internal management. This information will allow managers to make informed decisions resulting in more efficient operations and resource allocations within their agencies.

It is anticipated that the information generated by this system will result in better planning and resource

allocations for existing populations. It also will allow state agencies to reduce or eliminate duplication of services and to more effectively use currently existing resources. Additionally, agency directors will gain the ability to project the impact individuals served by one agency may have on their agency. Examples of this would be the sharing of the population demographics between the different levels of the school programs and adult service providers. This will allow directors to predict future needs with accuracy not permitted within the current system.

The major benefit of the centralized data system will be the ability to collapse information across agencies. This information will be of use concerning projecting resource needs for the future. Legislators would have accurate information concerning which types of services are being received by persons with disabilities as well as how many persons are receiving those services.

Individuals with disabilities will reap the benefits of this new system in many ways. They will have easier access to additional services through the information and referral section (part three) of the system. Eligibility for programs can be determined more quickly because of the individual histories contained in part one of the system. More resources may become available through the elimination, or more efficient use of, services across agencies. Finally, the individual will benefit from the improved ability of agencies and legislators to forecast future needs, resulting in a more efficient and effective social service system.

## VI. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain governmental mandate that requires all state agencies to develop and implement a central data collection system.

2. Convene an implementation work group, comprised of state agency information systems representatives, outside data experts and consumers to serve on an interagency data committee. The interagency data committee will identify the changes required within their respective agencies to implement the central system and render recommendations accordingly. The committee will conduct a feasibility study to address the following issues:

   a. An analysis of current data base systems utilizing an external evaluation methodology.

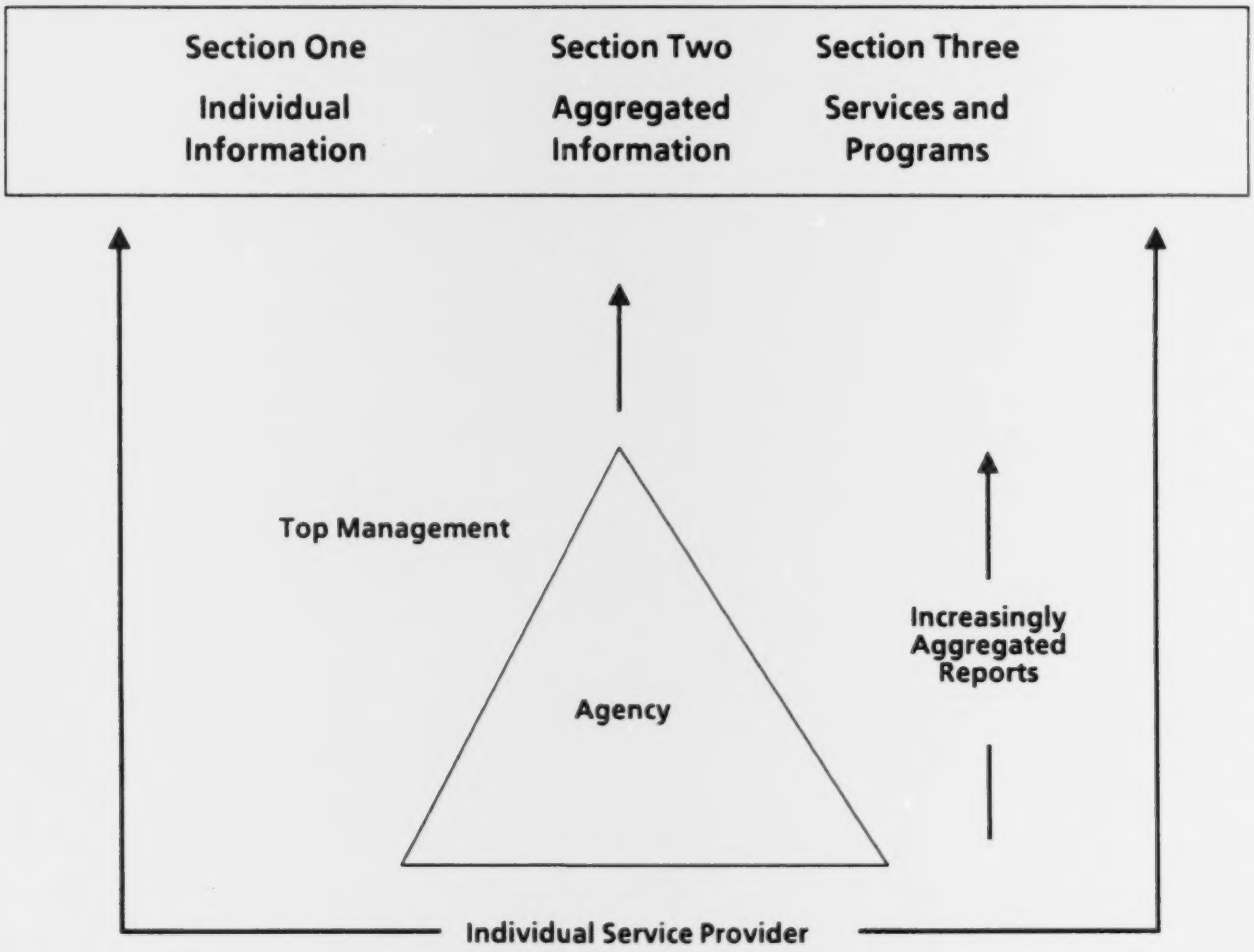
   b. Determination of an ideal data set as well as accompanying operational considerations.

c. An analysis of current legal requirements concerning confidentiality.

d. Determination of data elements currently collected by each agency and their commonalties.

e. Assure that the feasibility study is completed within twelve months.

## Figure 1: Centralized Data/Information System



**ISSUE: A BASIS FOR THE DEVELOPMENT OF COMMON INTERAGENCY GEOGRAPHIC BOUNDARIES.**

## I. VISION

A system of common interagency geographic boundaries will promote increased coordination and effectiveness of state-supported local services for persons with disabilities. Such a system would facilitate uniform data assimilation and consumer access to service options. Common geographic boundaries would enhance interagency coordination resulting in elimination of service gaps and duplication of services in local and regional areas. Endemic in this system would be reduced emphasis on artificial community agency boundaries.

## II. ISSUE DEFINITION

The current system of state supported services is fragmented and uncoordinated at the state, regional and local levels. This fosters substantial inequities which inhibit access and affects the quality of services and supports for consumers. The absence of common geographic boundaries for state agency programs also creates difficulty in collecting and aggregating data which is vital for projecting future needs.

## III. BACKGROUND

Interest relative to the development of uniform state agency boundaries has prevailed throughout the last three Administrations. Notably, during 1971 this interest culminated with Governor Ogilvie issuing Executive Order Number Seven directing state agencies to create common geographic boundaries. This Executive Order was based on recommendations developed by a Task Force on Regionalization appointed by the Governor. The Task Force recommended establishing five major regions with a provision that seven regions may be used by those state agencies wishing to use subregional structures. There was a subsequent flurry of activity which resulted in progress toward this end on the part of a few agencies. Over the years, however, this progress has eroded. Currently, uniform boundaries among state agencies simply do not exist (examples attached).

Evidence of informal activities to compensate for the discontinuity created by this nonuniformity is also apparent. An example of such efforts is clearly evident by the activities associated with an areawide Cabinet on Health and Social Services which has functioned in Southern Illinois for over 15 years. This Cabinet has incorporated the involvement of regional administrators from a dozen agencies. Its effectiveness has diminished in recent years due to the

fragmentation of state agency service areas. Nevertheless, its modest role in issue analysis, information exchange and service coordination has produced positive impacts in that area of the state. The prevalence of uncommon geographic boundaries affects all state agencies, creates isolation among these agencies, reduces public access to services and confuses and frustrates consumers. For example, in order to fully access their communities, persons with disabilities tend to rely upon public transportation systems. Local transit authorities establish their own geographic boundaries independent of one another. The absence of consistent coordination can significantly reduce community access. Additionally, the system promotes duplication of resource allocations inclusive of personnel, volunteers, and associated costs.

Finally, this discontinuity contributes to the continual absence of a strategic plan cooperatively developed by state agencies. Consequently, the prospect for producing positive systemic changes and progressive policies in the area of health and social services is greatly diminished.

## IV. ISSUE ANALYSIS

Non-uniform state agency boundaries promote the use of multiple service administration offices. This hampers consumer ability to access services. Services provided by community agencies are hindered because of the necessity to relate to numerous state agency representatives who operate from these multiple offices. Additionally, state agencies frequently utilize different eligibility criteria which further compounds problems related to service access. As a result, eligibility tends to be dictated by service availability within geographic boundaries rather than meet the individualized needs of consumers and their families. Standardization of geographic areas administered by state agencies is a worthy objective. This system would enhance the assimilation of data, facilitate maximum utilization of state services, and reduce geographic barriers for consumers.

## V. PROPOSED NEW MODEL

This would be an opportune time to once again examine the efficacy of establishing uniform geographic boundaries. As outlined in the 1971 Executive Order, counties could be grouped into a specified number of regions taking into consideration factors such as census, distance between service providers, transportational barriers, location of state office complexes and the availability of services. These defined geographic boundaries would be adhered to by all state agencies. Obviously, the success of any new model will require a policy mandate inclusive of legislation

directing this outcome. Cooperation among all state agencies in fulfilling this new mandate will be critical.

## VI. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate requiring common geographic boundaries for all state agencies.

2. Convene representatives from all state agencies to examine strategies that will result in uniform geographic boundaries. Focus of examination should include, but not be limited to, recommendations formulated by the 1971 Task Force on Regionalization.

3. Determine an ideal set of geographic boundaries (i.e. regions, counties) as well as accompanying operational considerations.

## Directory of Planning and Service Areas in Illinois

1. **Northwestern Illinois Area Agency on Aging**
   Janet B. Ellis, Executive Director
   4233 East State Street, Eastmoor Building
   Rockford, Illinois 61108
   815/226-4861

2. **Northeastern Illinois Area Agency on Aging**
   Charles D. Johnson, Executive Director
   Street Address:
   Kankakee Community College
   River Road, West Campus — Building 5
   Mailing Address:
   P.O. Box 809
   Kankakee, Illinois 60901
   815/939-0727
   Field Office:
   Building No. 6, Unit 39
   246 West Roosevelt Road
   West Chicago, Illinois 60185
   312/293-8990
   800-828-2000

3. **Western Illinois Area Agency on Aging, Inc.**
   Greta Brooks, Director
   729 34th Avenue
   Rock Island, Illinois 61201
   309/793-8800, 800/322-1851

4. **Central Illinois Agency on Aging, Inc.**
   Barbara M. Miller, Executive Director
   700 Hamilton Boulevard
   Peoria, Illinois 61603
   309/674-2071

5. **East Central Illinois Area Agency on Aging, Inc.**
   Mrs. Phyllis H. Pinkerton, Director
   1003 Maple Hill Road

   Bloomington, IL 61704-9008
   309/829-2065
   Information and Referral No. 800/322-0484

6. **West Central Illinois Area Agency on Aging**
   Lynn Niewohner, Director
   Street Address:
   1125 Hampshire Street
   Quincy, Illinois 62301
   Mailing Address:
   P.O. Box 428
   Quincy, Illinois 62306-0428
   217/223-7904
   Information and Referral No. 800/252-8027

7. **Project LIFE Area Agency on Aging, Inc.**
   Dorothy S. Kimball, Executive Director
   2815 West Washington, Suite 220
   Springfield, Illinois 62702
   217/787-6234
   Information and Referral Number:
   800/252-2918

8. **Southwestern Illinois Area Agency on Aging**
   Paul G. Walther, Ph.D., Executive Director
   Fairview Executive Plaza, Suite 170
   331 Salem Place
   Fairview Heights, Illinois 62208
   618/632-1333

9. **Midland Area Agency on Aging**
   Deborah Kulken, Director
   P. O. Box 1426
   Centralia, Illinois 62801
   618/532-1883
   Information and Referral Number: 618/532-1883

10. **Southeastern Illinois Area Agency on Aging, Inc.**
    Harold Morris, Director
    109 W. 6th St.
    Mt. Carmel, Illinois 62863
    618/262-8661

11. **Egyptian Area Agency on Aging, Inc.**
    John Smith, Executive Director
    108 S. Division St.
    Carterville, IL 62918
    (618) 985-8311

12. **Chicago Department on Aging and Disability**
    Donald R. Smith, Commissioner
    510 North Peshtigo Court
    Chicago, Illinois 60611
    312/744-4016 (VOICE)
    312/744-6777 (TDD)

13. **Suburban Area Agency on Aging**
    Jonathan Lavin, Executive Director
    600 West Jackson Blvd., Suite 600
    Chicago, Illinois 60606
    708-383-0258
    312-559-0616



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# service offices

## REGION 1

ALTON
ANNA
BELLEVILLE
BENTON
CARBONDALE
CARBONDALE (SIU)
EAST ST. LOUIS
GRANITE CITY
HARRISBURG
MARION
MT. VERNON
OLNEY

## REGION 2

BLOOMINGTON
CHAMPAIGN
CHAMPAIGN (U of I)
DANVILLE
DECATUR
JACKSONVILLE
MATTOON
QUINCY
SPRINGFIELD

## REGION 3

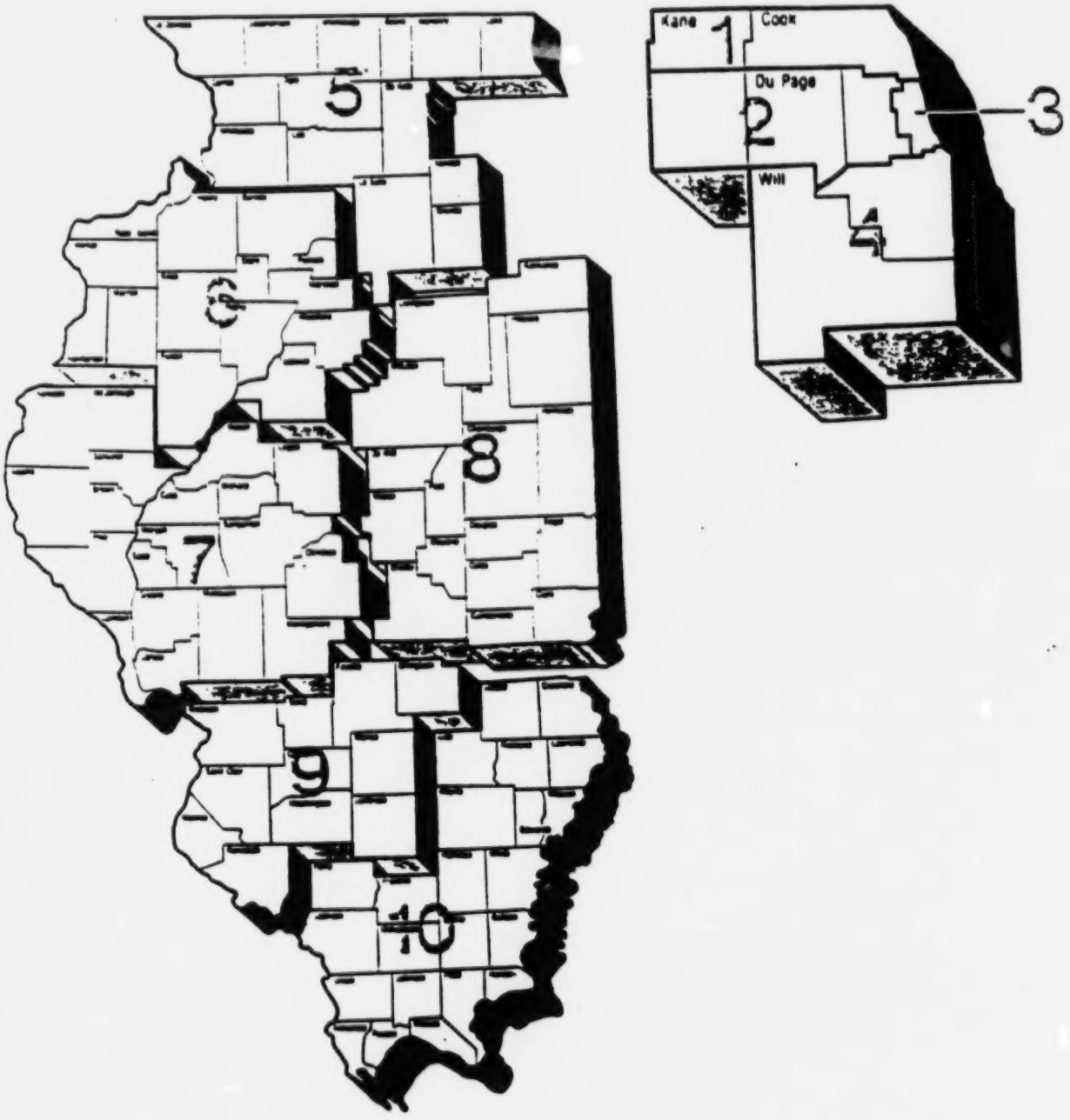
AURORA
DEKALB
ELGIN
FREEPORT
GALESBURG
JOLIET
KANKAKEE
LASALLE
MACOMB
PEKIN
PEORIA
ROCK FALLS
ROCKFORD
ROCK ISLAND

## REGION 4

CHICAGO - 160
CHICAGO - DIVISION
CHICAGO HEIGHTS
OAK PARK

CHICAGO - RANDOLPH
CHICAGO - LAWRENCE
CHICAGO - N. WESTERN
DOWNERS GROVE
MT. PROSPECT
WAUKEGAN

Illincis Department of
Public Aid Regions



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# Division of Services for Crippled Children

## Regional Office Locations

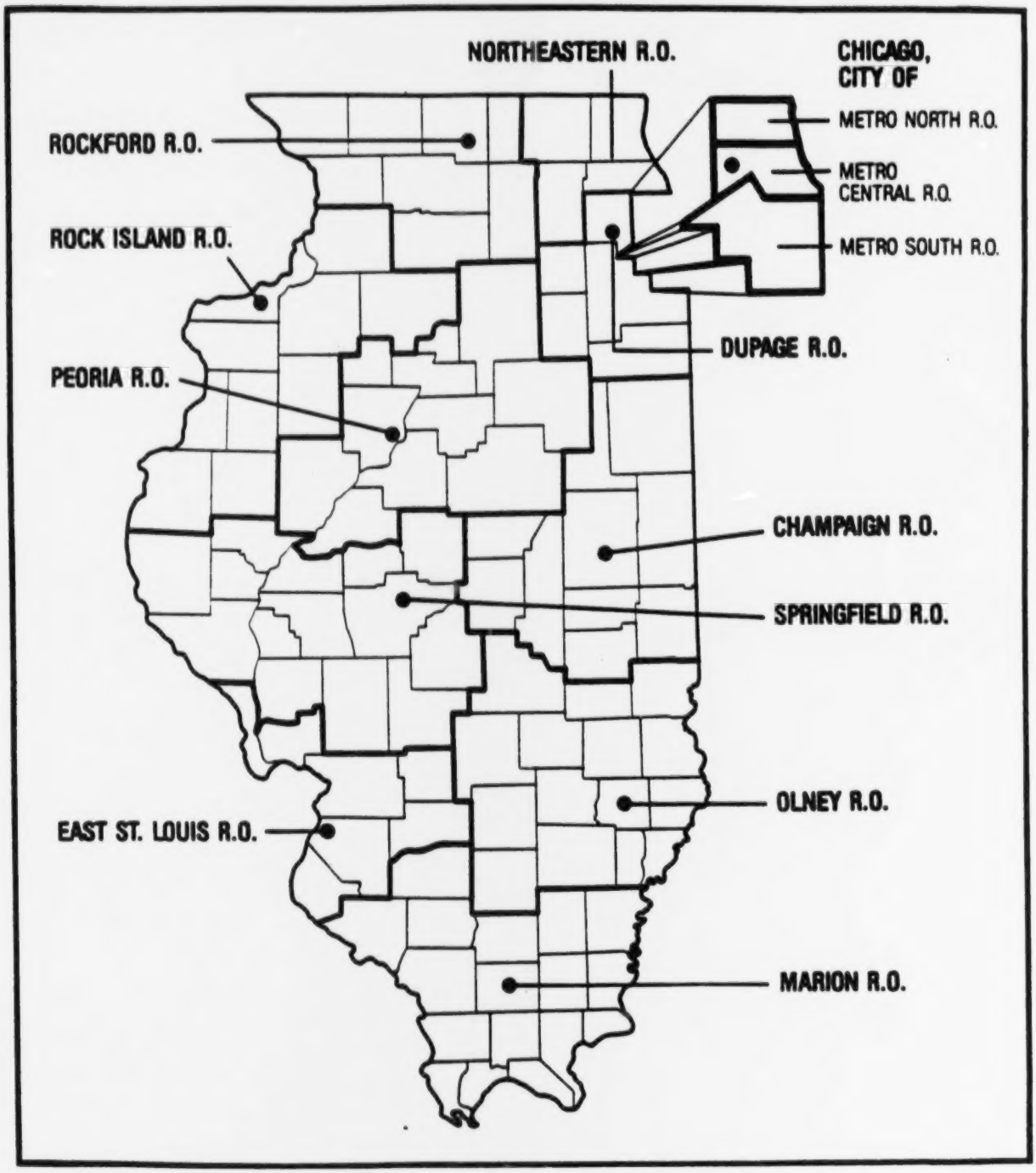
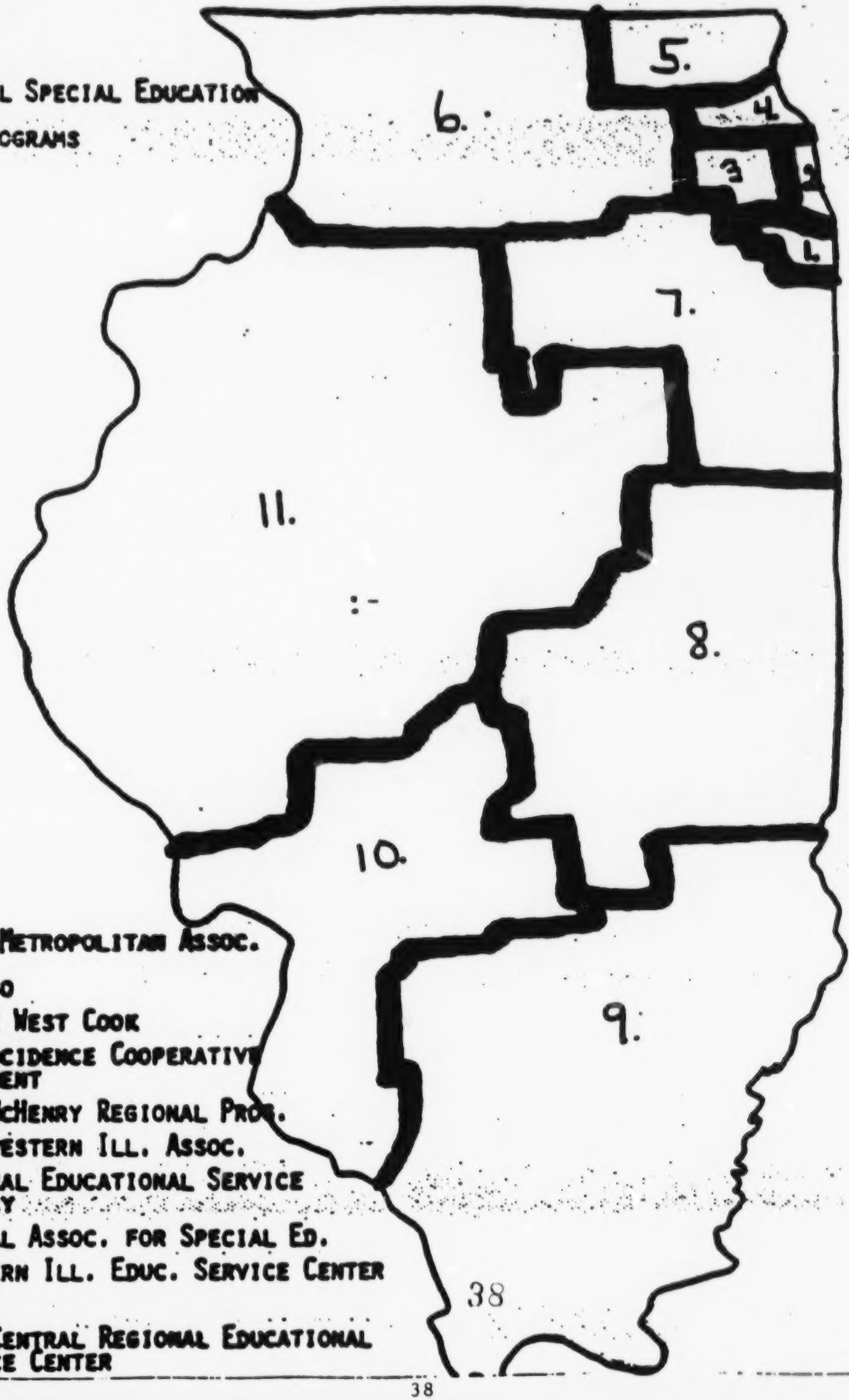



Figure 2

## Regional Special Education Programs




1. South Metropolitan Assoc.
2. Chicago
3. DuPage West Cook
4. Low Incidence Cooperative Agreement
5. Lake-McHenry Regional Prog.
6. Northwestern Ill. Assoc.
7. Regional Educational Service Agency
8. Central Assoc. for Special Ed.
9. Southern Ill. Educ. Service Center
10. TEMCO
11. West Central Regional Educational Service Center



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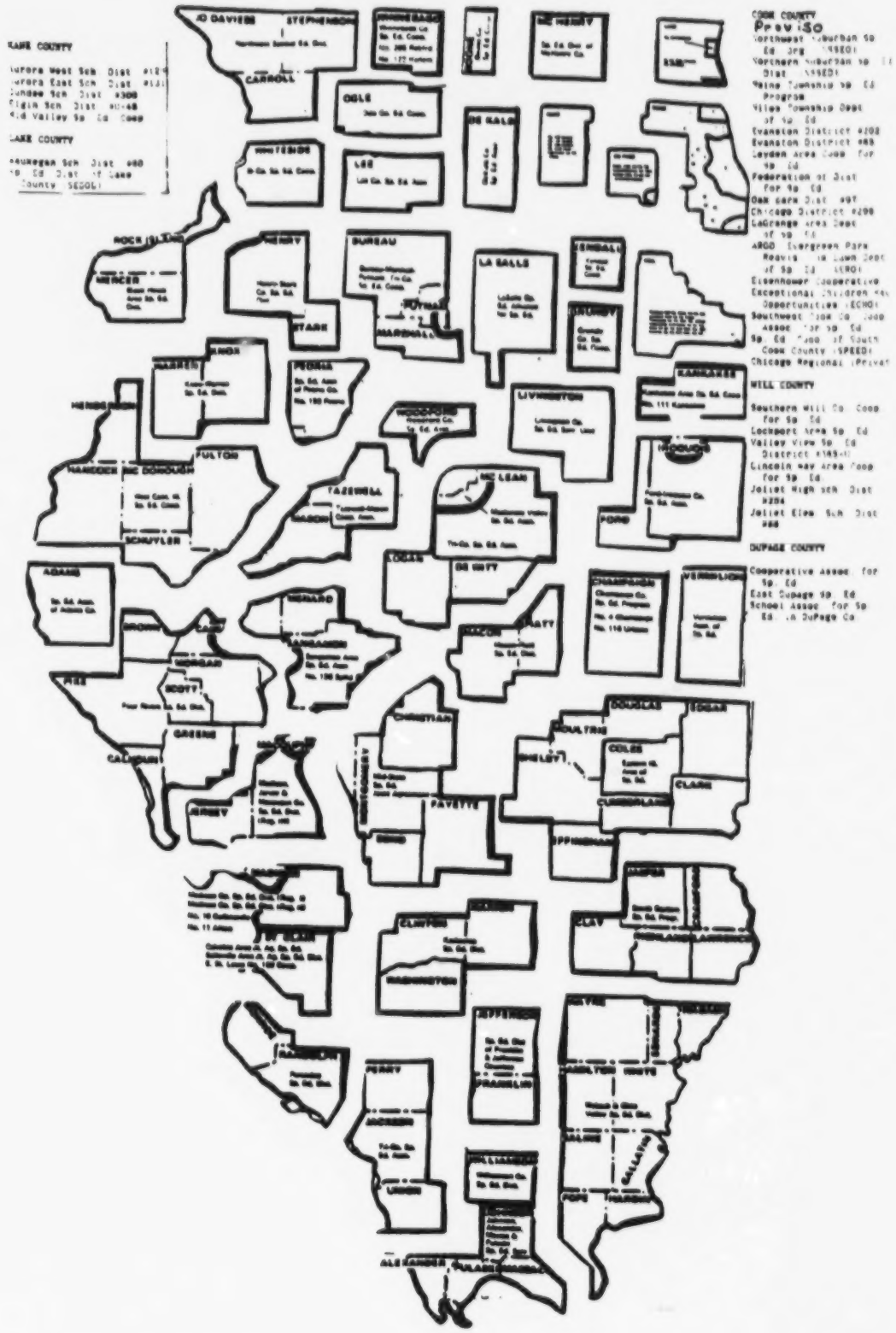




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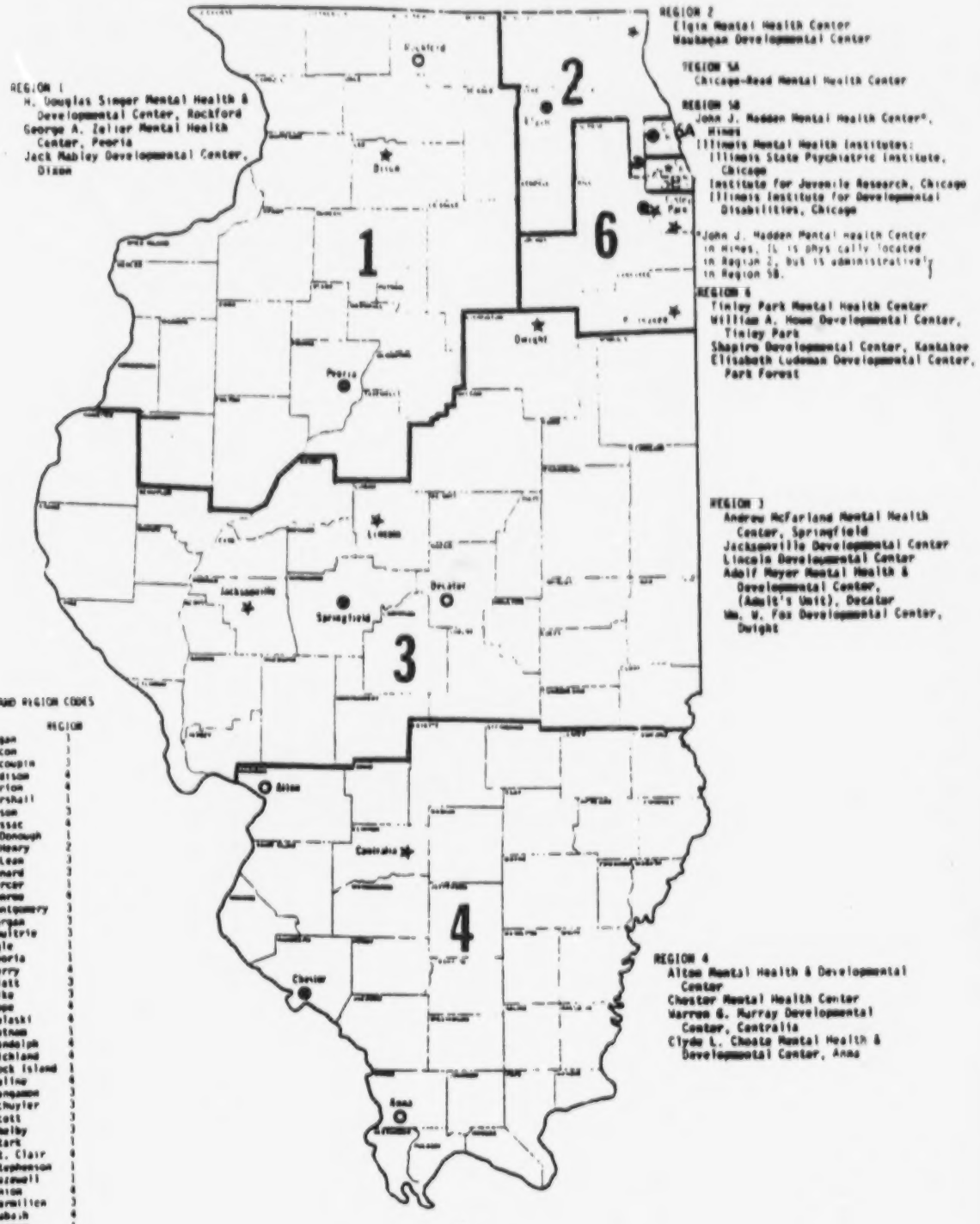
ILLINOIS DEPARTMENT OF MENTAL HEALTH & DEVELOPMENTAL DISABILITIES

# REGIONAL MAP




ILLINOIS COUNTIES WITH COUNTY AND REGION CODES

| CO. | | REGION |
|---|---|---|
| 1 | Adams | 3 |
| 2 | Alexander | 4 |
| 3 | Bond | 4 |
| 4 | Boone | 1 |
| 5 | Brown | 3 |
| 6 | Bureau | 1 |
| 7 | Calhoun | 3 |
| 8 | Carroll | 1 |
| 9 | Cass | 3 |
| 10 | Champaign | 3 |
| 11 | Christian | 3 |
| 12 | Clark | 4 |
| 13 | Clay | 4 |
| 14 | Clinton | 4 |
| 15 | Coles | 3 |
| 16 | Cook(ex.Chg.)2 | |
| | Cook(ex.Chg.)5 | |
| 17 | Crawford | 4 |
| 18 | Cumberland | 3 |
| 19 | DeKalb | 1 |
| 20 | DeWitt | 3 |
| 21 | Douglas | 3 |
| 22 | DuPage | 6 |
| 23 | Edgar | 3 |
| 24 | Edwards | 4 |
| 25 | Effingham | 4 |
| 26 | Fayette | 4 |
| 27 | Ford | 3 |
| 28 | Franklin | 4 |
| 29 | Fulton | 1 |
| 30 | Gallatin | 4 |
| 31 | Greene | 3 |
| 32 | Grundy | 6 |
| 33 | Hamilton | 4 |
| 34 | Hancock | 3 |
| 35 | Hardin | 4 |
| 36 | Henderson | 1 |
| 37 | Henry | 1 |
| 38 | Iroquois | 3 |
| 39 | Jackson | 4 |
| 40 | Jasper | 4 |
| 41 | Jefferson | 4 |
| 42 | Jersey | 3 |
| 43 | Jo Daviess | 1 |
| 44 | Johnson | 4 |
| 45 | Kane | 2 |
| 46 | Kankakee | 6 |
| 47 | Kendall | 7 |
| 48 | Knox | 1 |
| 49 | Lake | 2 |
| 50 | LaSalle | 1 |
| 51 | Lawrence | 4 |
| 52 | Lee | 1 |
| 53 | Livingston | 3 |
| 54 | Logan | 3 |
| 55 | Macon | 3 |
| 56 | Macoupin | 3 |
| 57 | Madison | 4 |
| 58 | Marion | 4 |
| 59 | Marshall | 1 |
| 60 | Mason | 3 |
| 61 | Massac | 4 |
| 62 | McDonough | 1 |
| 63 | McHenry | 2 |
| 64 | McLean | 3 |
| 65 | Menard | 3 |
| 66 | Mercer | 1 |
| 67 | Monroe | 4 |
| 68 | Montgomery | 3 |
| 69 | Morgan | 3 |
| 70 | Moultrie | 3 |
| 71 | Ogle | 1 |
| 72 | Peoria | 1 |
| 73 | Perry | 4 |
| 74 | Piatt | 3 |
| 75 | Pike | 4 |
| 76 | Pope | 4 |
| 77 | Pulaski | 4 |
| 78 | Putnam | 1 |
| 79 | Randolph | 4 |
| 80 | Richland | 4 |
| 81 | Rock Island | 1 |
| 82 | Saline | 4 |
| 83 | Sangamon | 3 |
| 84 | Schuyler | 3 |
| 85 | Scott | 3 |
| 86 | Shelby | 3 |
| 87 | Stark | 1 |
| 88 | St. Clair | 4 |
| 89 | Stephenson | 1 |
| 90 | Tazewell | 1 |
| 91 | Union | 4 |
| 92 | Vermilion | 3 |
| 93 | Wabash | 4 |
| 94 | Warren | 1 |
| 95 | Washington | 4 |
| 96 | Wayne | 4 |
| 97 | White | 4 |
| 98 | Whiteside | 1 |
| 99 | Will | 6 |
| 100 | Williamson | 4 |
| 101 | Winnebago | 1 |
| 102 | Woodford | 1 |
| 103 | Out of State | |
| 104 | County unknown | |
| 105 | Chicago (No.)5A | |
| | Chicago (So.)5B | |

LEGEND
- Mental Health Center
- Mental Health and Developmental Center
- Developmental Center for the Developmentally Disabled
- Illinois Mental Health Institutes

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**Regional Map**

**Illinois Department of Children and Family Services**

Stars indicate regional headquarters.



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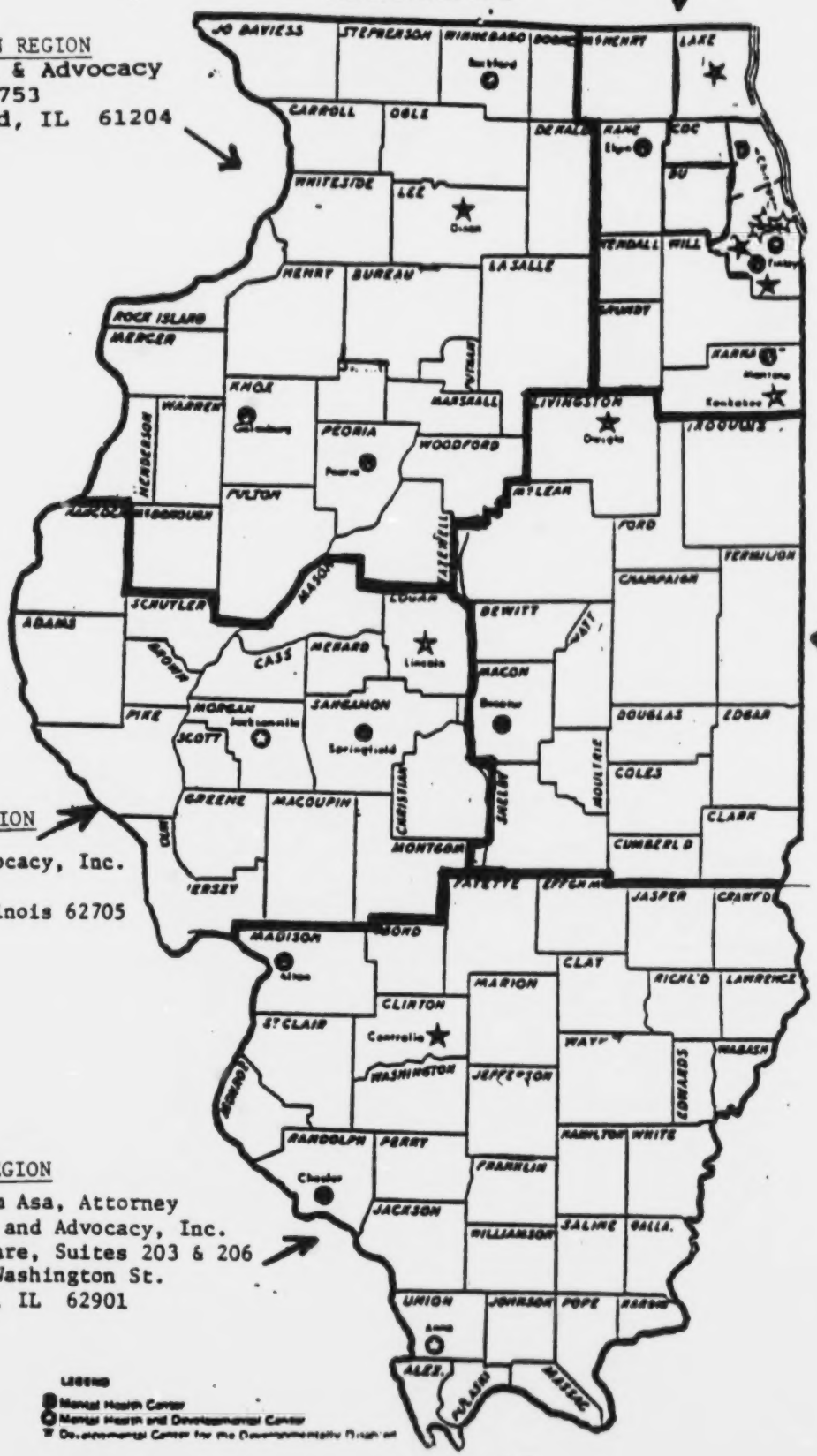
PROTECTION AND ADVOCACY

NORTHEASTERN REGION
Protection & Advocacy
11 E. Adams, Ste. 1200
Chicago, IL. 60603

REGIONAL MAP

NORTHWESTERN REGION
Protection & Advocacy
P.O. Box 3753
Rock Island, IL 61204




EAST CENTRAL REGION
Protection & Advocacy
115 N. Neil, Suite 419
Champaign, IL 61820

WEST CENTRAL REGION
Protection & Advocacy, Inc.
P.O. Box 276
Springfield, Illinois 62705

SOUTHERN REGION
Mr. William Asa, Attorney
Protection and Advocacy, Inc.
Bening Square, Suites 203 & 206
103 South Washington St.
Carbondale, IL 62901

LEGEND
Mental Health Center
Mental Health and Developmental Center
Developmental Center for the Developmentally Disabled

REGIONAL OFFICES
(Service Locations)

1. Rockford Regional Office
   Singer MHC - Hawthorn Hall
   4402 North Main (Box 62)
   Rockford, IL 61105
   (815) 987-7657
   FAX: (815) 987-7227

2. Peoria Regional Office
   416 St. Mark Court, Suite 403
   Peoria, IL 61603
   (309) 671-3350
   FAX: (309) 671-3352

3. Chicago Regional Office
   1735 West Taylor
   Chicago, IL 60612
   (312) 996-1650
   FAX: (312) 829-9181

4. South Suburban Regional Office
   1010 Dixie Highway
   Chicago Heights, IL 60411
   (708) 709-3070
   FAX: (708) 709-3097

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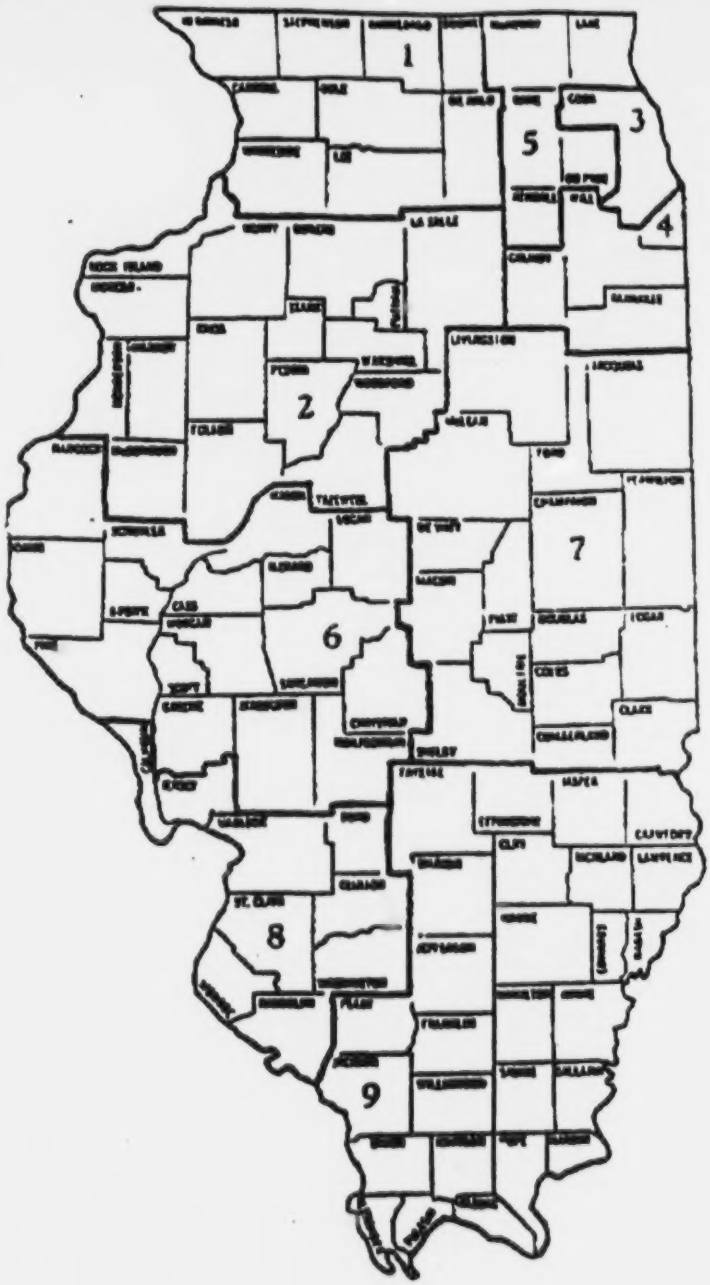

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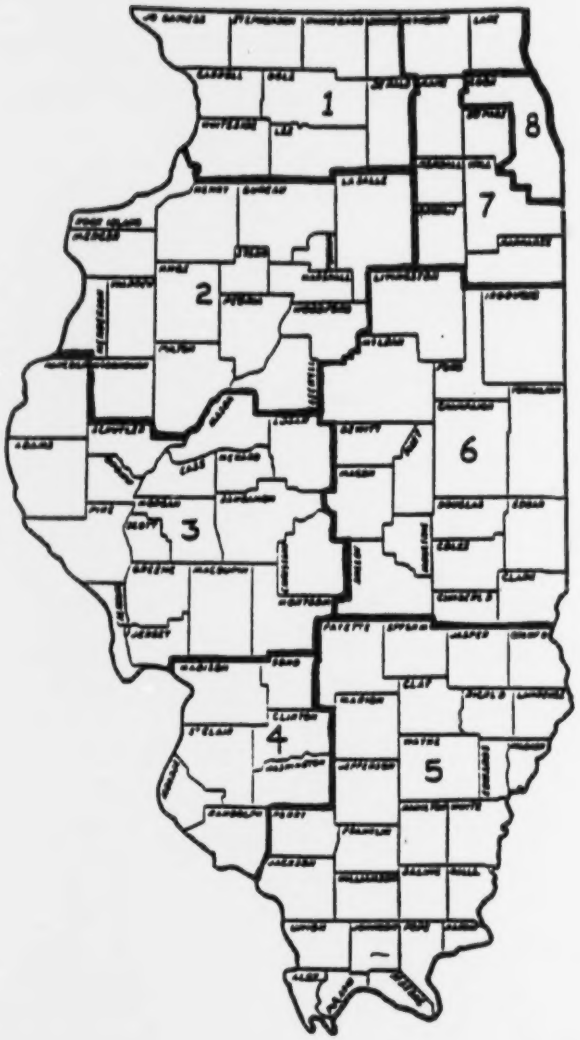


**LEGEND**
Life Safety Section - Architects
Resident Care Section - Nurses & Nutritionists
Institutional Health & Safety - Sanitarians
*BELLWOOD - Suburban Cook County
**CHICAGO - City of Chicago


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**ISSUE: A BASIS FOR A SINGLE, INTERAGENCY, CONSUMER-BASED PLANNING AND ADVISORY BODY WITH SUBGROUPS FOR EACH STATE AGENCY.**

## I. VISION

Illinois will have one single, interagency, consumer-empowered Advisory Board to assist state government in planning, coordinating and implementing strategies to meet the needs of all persons with disabilities.

## II. BACKGROUND

Currently, there is no single advisory body which coordinates the activities of the various advisory groups within state agencies representing the needs of all persons with disabilities. Consequently, a common value base does not exist among all advisory bodies. State agencies utilize numerous advisory bodies which focus on special issues important to the agency and persons served by that agency. **More than eighty advisory bodies currently serve the eleven Illinois agencies providing the majority of services to persons with disabilities.** These agencies include: the Illinois Department of Rehabilitation Services (DORS); the Illinois Department of Mental Health and Developmental Disabilities (DMHDD); the Illinois Department on Aging (DOA); the Illinois State Board of Education, Department of Special Education (ISBE); the Illinois Department of Public Aid (DPA), Bureau of the Budget (BoB), Illinois Department of Children and Family Services (DCFS), Illinois Department of Public Health (DPH), Guardianship and Advocacy (G & A), Protection and Advocacy (P & A) and the Division of Services for Crippled Children (DSCC).

In addition to the sheer numbers of advisory bodies, the issue is further complicated by their various organizational placements, orientations and mandates. Depending upon organizational placement, advisory bodies may report to the agency director or to units within the agency. Some advisory bodies are service oriented while others are management oriented or consumer oriented. Some disability-specific advisory bodies have been formed because of pressure exerted by their special interest groups, not because of the size of their constituency. Some advisory bodies exist because of an internal need recognized by the organization. Other advisory bodies exist due to state or federal mandates (which may or may not reflect needs). The existence of these various advisory bodies is important; however, a common value base must drive their activities in order to maximize their collective effectiveness. An umbrella advisory board would assure that a common value base prevails.

In addition to the many agency advisory bodies, there are six Councils which also advise state government about issues concerning persons with disabilities. These include: the Illinois Planning Council on Developmental Disabilities (IPCDD), the Illinois Council on Aging, the Planning Council on Mental Health (effective April 1, 1991), the Citizens Council on Mental Health and Developmental Disabilities (Citizens Assembly), the Rehabilitation Services Advisory Council (RSAC) (also advising the DORS Director) and the Advisory Council on Education of Handicapped Children. The Director of each of these Councils, with the exception of the Director of the Citizens Assembly, who is appointed by the General Assembly, is appointed by the Governor. Each is responsible for developing and submitting to the Governor and General Assembly, plans relating to services for persons with disabilities. Although informal consultation occurs among these Councils, no attempt is made to formally coordinate or integrate their activities or recommendations.

## III. ISSUE ANALYSIS

Advisory bodies may serve various functions. Some are largely established to provide technical assistance or consultation from experts or individuals with special skills or knowledge. Others are composed of persons representing a constituency of persons served by the agency (i.e. consumers).

Adequate consumer representation of all persons with disabilities is difficult to achieve due to the wide variety of interests requiring representation. A disability can be defined generally (i.e. physical, developmental), categorically (i.e. cerebral palsy, schizophrenia) or according to the services required by the disability (i.e. special transportation, medical, mental health). Even if it were possible to define a consortium which would adequately include all disabilities, finding and involving appropriate representatives of each group would present considerable challenge. Individual state agencies do not serve persons with all types of disabilities, therefore, they cannot adequately represent them in an advisory capacity. Consumers must be present on advisory bodies because of their unique expertise.

## IV. PROPOSED NEW MODEL

The Executive Branch should have one umbrella advisory body comprised of the Director from each state and federally supported agency providing services for persons with disabilities as well as an equal number of consumers. These agencies should include, but not necessarily be limited to: DORS, DMHDD, DOA, ISBE, DPA, BoB, G & A, P & A, DCFS, DPH and

DSCC. This body would provide technical assistance to the Executive Branch and work with the Governor's Planning Office to develop a strategic plan to coordinate services for all persons with disabilities. The recommendations formulated by this advisory board will assure input from interested consumer groups and service providers. It would also serve as the central information linkage to all Advisory groups now serving state agencies. This advisory board would have the power to call public hearings. All proposed recommendations would be made available for public comment prior to final submission. These comments would be incorporated into the final submission.

## V. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate to develop a non-agency-based committee to:

    a. Draft a mission for an interagency consumer-focused advisory board.

    b. Assure that all state and federally funded agencies providing services for persons with disabilities are represented on the advisory board.

    c. Assure adequate representation of consumers or consumer groups to be represented on the advisory board.

    d. Develop guidelines which will govern the advisory board in its review and development of recommendations for planning and policy which include:

        1. organizational structure (i.e. appointment of chairperson), and

        2. the mandatory inclusion of consumers and consumer groups in the formation of task forces, committees, ad hoc groups, etc.

# ISSUES RELATED TO THE IMPLEMENTATION OF A STRATEGIC PLAN

**ISSUE: A BASIS FOR AVOIDING/ALLEVIATING DUPLICATION OF SERVICES.**

I. VISION

All agencies will work cooperatively to enable people with disabilities to receive quality services, to build a system that is accountable to the citizens of the state and empowers people to have control over their own lives.

II. ISSUE DEFINITION

Among the barriers to providing services for persons with disabilities is a lack of coordination and cooperation between state agencies. This lack of coordination often creates duplication, confusion and gaps in services. This is particularly true for residential facilities which are funded by the Department of Public Aid, certified by the Department of Public Health and monitored by the Department of Mental Health and Developmental Disabilities. Interagency coordination is a way to achieve more efficient management and cost effectiveness in the service delivery system. There must be a link between state agencies in order to coordinate, operationalize and direct their resources and minimize duplication of services. Further, services must meet the individual needs and preferences of persons with disabilities.

III. BACKGROUND

State agencies provide an array of services for citizens with disabilities. One agency may administer all income maintenance programs while home services for the elderly may be administered by three separate agencies. Lack of coordination among the various state agencies can result in duplication of services, which makes problem solving at the community level extremely difficult. Presently, the Departments of Public Aid, Rehabilitation Services and Mental Health and Developmental Disabilities are all serving persons with disabilities through a program called Supported Employment. The current regulations applied to Supported Employment are duplicative and in some cases contradictory. Interagency coordination would prevent this situation from occurring and eliminate the frustration and confusion experienced by consumers.

In recent years, the need for interagency coordination has received attention at the local, state and national level. Many state agencies have attempted to reduce duplication and inefficiency. State and federal legislation requires that people with disabilities be provided appropriate services,

however legislation does not mandate interagency linkage to assure that a comprehensive service system inclusive of generic community-based services is provided. There are requirements which relate to coordination of services across state agencies. Public Law 94-142, Vocational Amendments of 1976, states that safeguards and assurances should be in place to strengthen interagency relationships.

Among the underlying themes of the Illinois **1990 Report To Congress** was that one of the greatest barriers to providing quality services for persons with disabilities at the federal and state level was the lack of coordination between state agencies.

Many consumers are frustrated and confused when trying to receive services from various state agencies. It is believed that as state agencies begin to network, effective coordination will result in improved services and with fewer individuals becoming lost in the system. There are arguments which state that one way to alleviate duplication of services is to have a single point of entry into the state system for people with disabilities where they can go to receive information about, and apply for, appropriate services.

It is critical that the key agencies facilitate creating systemic changes which promote interagency linkage. Such system changes must ensure that roles and responsibilities relative to service provisions are delineated. These agencies are: Department of Public Aid, Department of Public Health, Department of Children and Family services, Department of Mental Health and Developmental Disabilities, Department of Rehabilitation Services, Division of Services for Crippled Children, Department of Alcoholism and Substance Abuse, Bureau of the Budget, Guardianship and Advocacy, Protection and Advocacy and the State Board of Education. Alleviating duplication of services can not be achieved without the commitment of staff and administrators at all levels within these agencies.

## IV. ISSUE ANALYSIS

Among the chief concerns of public officials as they design and review services and service delivery systems is the efficiency of current services. The issue of efficiency must be considered within the following context:

- Is taxpayer money being appropriately expended and managed?
- Is the program performing at an acceptable level?
- How many people are being served?

- How well are their needs being met?
- What is the public's perception of the agency and its services?

Most important in evaluating the efficiency of state-funded services and service delivery systems is whether or not persons receiving or intending to receive those services are satisfied.

Information suggests that the lack of coordination among state agencies and some aspects of duplication have resulted in a less efficient service delivery system.

In examining the issue of service duplication the following should be considered:

- Is unnecessary service duplication actually occurring?
- To what extent can duplicated services be unified?

Clearly there are services which are essentially similar in nature such as employment programs and residential programs, which are provided by different state agencies. Persons with disabilities may be eligible to receive residential support services funded by DMHDD, i.e. CILA, DPA, i.e. ICF-DD or DORS, i.e. home services program. Similarly, vocational services are available through each of these agencies. However, there is no evidence to suggest that duplication of service availability is resulting in the duplication of service provision, i.e. the same person does not receive residential services from both DPA and DMHDD. Duplication of this nature could be viewed as positive, as it allows for consumer choice.

A second area of duplication to consider is whether similar aspects of services and/or service delivery systems can be streamlined. Through consolidation or coordination, the entire system of service delivery for persons with disabilities would become more efficient. This efficiency could be achieved through improved inter-agency planning and consistent intake functions and appeal and due process procedures. As appropriate, similar functions performed by a variety of state agencies would be consolidated.

The designation of a lead state agency for a particular service category may assist in this effort. This agency need not provide all services within a designated category, but may be delegated responsibility for coordinating the various efforts of those state agencies which are involved. In order for this strategy to be effective, the lead state agency must be provided specific responsibilities and authority.

The coordination of services should also be analyzed from the consumer perspective. One outcome of the above strategies may be a more user friendly service delivery system for those who actually require the service. These strategies are clearly targeted toward more systemic and managerial issues related to service delivery. Any action taken to avoid duplication and improve the coordination of services for persons with disabilities must include steps which specifically address how persons access and coordinate those services received by multiple state agencies. Restructuring policies and procedures which guide the dissemination of information regarding service availability; the processes by which people can access those services; and mechanisms for ensuring that people are receiving individualized services may be the best available guarantee that services are being coordinated and unduplicated. Further, these policies and procedures must consider the cultural and language diversity that prevent individuals from accessing services.

## V. PROPOSED NEW MODEL

The issues which have been raised support the need for reviewing and restructuring services and service delivery in Illinois. While the service system is clearly not in a state of disarray, it is equally clear that resources, although limited, may be more efficiently used to better address individual needs and circumstances.

In order to effectively avoid the duplication of services and ensure coordinated delivery of those services available, a new model must be adopted by the state. This model should have as its cornerstones participation, flexibility, creativity, and accountability to consumers, taxpayers and legislators. This model should address service content, structure and the stated purpose for providing coordinated services which enable persons to maximize their opportunities for independence, integration and productivity.

The first step in this process is to establish mechanisms for ensuring that consumers are actively involved when services are being designed, developed and directed. There is an abundance of recent data within Illinois regarding consumer satisfaction with services, their recommendations for change in services and a description of unmet needs. This information must be considered by policymakers, legislators and state agency administrators as they review disability-related services within Illinois. By relying upon consumer input, duplication of services could be avoided in the future, as people who use services would likely have a better idea of how services can complement each other, rather than conflict with each other.

A second aspect of this new model would be an approach to services and service delivery which emphasizes flexibility and creativity. By emphasizing these two qualities, services can be better coordinated to accommodate individual as well as regional circumstances. Persons in rural areas may have different needs within a service category than persons in urban areas. Similarly, persons with a severe disability may have different needs for a service than other eligible persons whose disability is less severe. A service delivery model which encourages flexibility within broad parameters will result in greater efficiency for those using as well as funding the service. Additionally, flexibility within services will contribute to a more coordinated service system as persons with disabilities have the opportunity to tailor a service package to fully meet their individual needs.

Presently, public accountability for services is difficult to achieve. An important reason for this is a lack of information on the part of the general public as well as consumers regarding service availability, access to services and information regarding entitled services. In the absence of this type of information, avoiding service duplication is further complicated. Also problematic is the coordination and consolidation of services or service functions.

A concerted effort on the part of all the major stakeholders inclusive of state agency personnel, consumers of services, advocacy groups, and legislators must be initiated. This major campaign must promote available services, instruct and assist consumers concerning access, and identify unmet needs.

A third aspect to consider in this proposed new model would be to designate the Executive Branch to be responsible for initiating a process to coordinate services between various state agencies. A liaison to the Governor's Office should act as a catalyst for recommending and ensuring coordination of services.

Finally, Illinois must assure that services for persons with disabilities are driven by clear and consistent values. Policymakers must recognize the distinction between society and the economy. Values upon which polices are based is what separates the two. The mission and values of disability-related services must be closely tied to the promotion of independence, productivity and integration. A system based upon these values would be a major step toward addressing the issues of service duplication and coordination.

## IV. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate requiring the formation of a task force comprised of consumers and their families, community provider agencies, state agency

representatives, legislators and the Governor's Office. This task force will be charged with the development of a coordinated plan to address the issues of interagency service duplication and service coordination.

The resulting plan will assure that a liaison with the Governor's Office is designated to insure coordination of services between the various state agencies serving persons with disabilities.

**ISSUE: COORDINATION OF STAFF DEVELOPMENT AND TRAINING AMONG STATE AND COMMUNITY AGENCIES PROVIDING SERVICES AND SUPPORTS FOR PERSONS WITH DISABILITIES.**

## I. VISION

Coordination of staff development and training efforts among state and community agencies will positively impact the lives of persons with disabilities and their families. In order to obtain and maintain services, persons with disabilities and their family members, more often than not, must relate to multiple agencies at the state and community levels. Multiple state agency and community organization personnel will have the same value, operational and technological base in keeping with current research and accepted best practice. This will facilitate persons with disabilities living lives comparable to their peers without disabilities. This will be accomplished by establishing an in-service central administrative unit on Staff Development and Training for Working with Persons with Disabilities. College and university expertise will be incorporated to develop preservice staff development and on-going training. Individuals employed by state agencies and community organizations receiving state and/or federal funds will be required to participate in in-service staff development and training annually.

## II. ISSUE DEFINITION

When needing services, persons with disabilities and their families must relate to multiple state and community agencies. When these multiple agencies do not share the same value, operational and technological base, services are fragmented and confused, thus leading to service duplication, service denial, service gaps, cost inefficiency and ineffectiveness. State and community agencies are required to have staff development and training programs as mandated by their funding sources. These development and training programs, however, are directed by the rules and regulations governing the individual funding source rather than being value, operational, and technologically based. Finally, staff in state agencies and community organizations have wide and varied educational backgrounds that are generally unrelated to providing services and supports for persons with disabilities. This results in state and community agencies not having an educated and trained employee pool. One factor in the lack of training is that no career development programs are provided by the state's two year community colleges and four year universities.

## III. BACKGROUND

Illinois has no coordinated system of staff development and training for individuals providing leadership, supervision and direct service at the state and community agency level. Furthermore, Illinois has not established comparable standards nor educational requirements across all state and community agencies serving persons with disabilities.

A coordinated and unified statewide in-service unit will impact employees in all state agencies and community organizations which provide services and support for persons with disabilities. A preservice training program will impact Illinois' regional community college and university systems.

The development of a coordinated and unified statewide in-service unit could be financially supported by state and community funds currently designated for staff development and training. When funds are tight, agencies typically reduce or eliminate staff development funds in favor of funds more directly related to services for individuals with disabilities. Additional funds may be required to assure the development of an effectively coordinated and unified staff development and training unit.

The development of preservice training in the state's universities and community colleges for individuals interested in working with persons with disabilities will be more costly, as no such training or associated certification currently exists. Weighed against the cost, however, must be the state's interest in the benefit to Illinois citizens with disabilities when individuals employed to support them are educated and have a value, operational and technological base prior to employment. When individuals are trained and prepared prior to employment, an increase in collective personnel related costs must be anticipated. Although increased costs would be realized, an increase in employee-paid tax revenues will also be generated.

## IV. ISSUE ANALYSIS

The concept of a value, operational and technologically based educated work force serving and supporting persons with disabilities will not be an issue. The concept of statewide coordinated and unified in-service and preservice staff development and training will also not be an issue. Ownership of staff development and training dollars will be an issue. The cost, ownership and designees of preservice training programs will also be an issue.

## V. PROPOSED NEW MODEL

The proposed new model is two-fold, involving (1) a

coordinated and unified in-service staff development and training effort among state and community agencies, and (2) a preservice program offered by community colleges and universities.

Coordinated and unified in-service staff development and training will be accomplished by the establishment of a central administrative unit on Staff Development and Training for Working with Persons with Disabilities (SDTD). Funding traditionally provided state agencies and community organizations responsible for providing services and support for persons with disabilities and their families will be directed toward the support of the SDTD. The SDTD will be responsible for working with designated colleges and universities. The Illinois Planning Council on Development Disabilities (IPCDD) will be responsible for formalizing relationships with Illinois colleges and universities that have the expertise to continually provide the SDTD with current research, information and personnel resources regarding current best practices and the provision of life-span services for persons with disabilities. College and university expertise is required in the following areas: family support and life-span transition, school and community integration and inclusion, employment, housing and instructional and behavioral technology. The SDTD will have staff development and training subunits in each of the aforementioned areas.

The SDTD as a whole and all subunits will provide staff development and training to state agencies and community organizations providing services and supports. All staff development and training will be reflective of a common value, operational, and technological base. This includes, but is not limited to, the following state agencies: Mental Health and Developmental Disabilities, Rehabilitation Services, Public Aid, Public Health, Division of Services for Crippled Children, Department on Aging, State Board of Education, Bureau of the Budget, Protection and Advocacy, Guardianship and Advocacy and Children and Family Services. Such training will consistently assure that persons with disabilities and their families receive supports and services essential for preserving the quality of life in the community. In addition, community organizations providing services and supports will also receive staff development and training services from the SDTD. Figure 1 illustrates this configuration. Both state agency and community organization personnel will be required to obtain a designated number of earned units or credits annually, in accordance with their individual professional or paraprofessional training needs.

The SDTD will be responsible for annually reporting the fiscal year's accomplishments and also projecting staff development needs to the Governor and to the legislature.

The second component, preservice training, will be offered at community colleges and universities strategically located throughout Illinois. Community colleges will offer a two year Associate Degree for the preparation of personnel who will be directly employed in supporting persons with disabilities in employment, housing, recreation, schools, communities and family. Colleges and universities will offer a four year Bachelor Degree preparing personnel for leadership and supervisory responsibilities in state agencies and community organizations. Figure 2 illustrates this configuration.

## VI. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate for a coordinated and unified staff development and training unit.

2. Develop an advisory body to study and provide recommendations regarding the location of a coordinated and unified staff development and training unit and to study and make recommendations regarding their comparative costs in the establishment and maintenance of the unit against currently available staff development and training funds in state agencies and community organizations.

3. Obtain consultants having expertise in instructional technology to guide the advisory body in order to maximize training time, mastery of concepts and professional-specific technology.

4. Develop an advisory body to study and make recommendations regarding designated university expertise and individual university relationships to the unit.

5. Develop a task force representing community college and university deans and other personnel, legislators, state agencies and community organizations to determine the most efficacious way of developing a two year Associate Degree for individuals working directly with persons with disabilities. Development of a four year Bachelor Degree to complement the Associate Degree will also be a priority for this task force.

6. Commission a study to determine the short and long term fiscal impact of offering a two year Associate and a four year Bachelor Degree for individuals working with persons with disabilities.

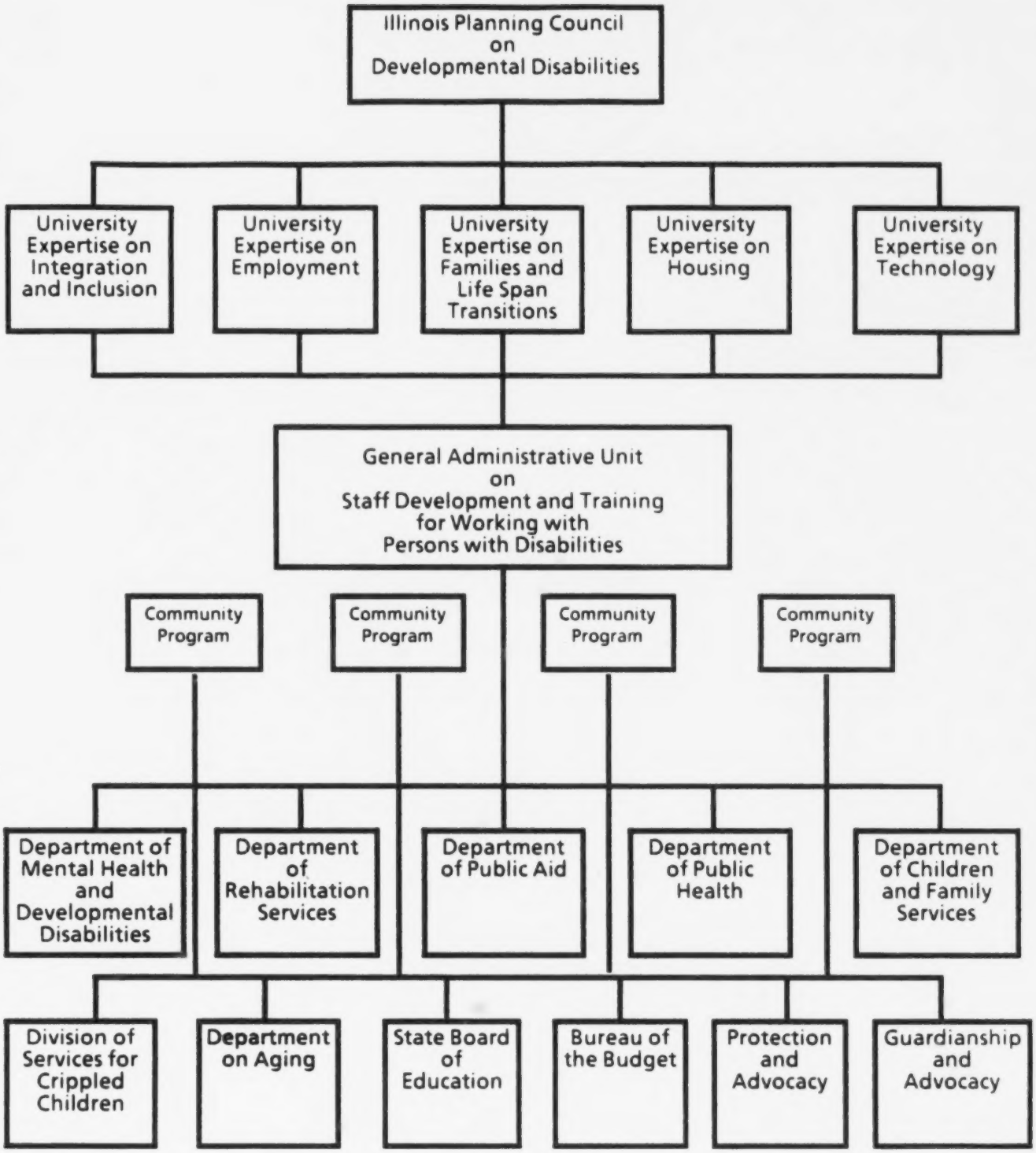
Illinois Planning Council on Developmental Disabilities
University Expertise on Integration and Inclusion
University Expertise on Employment
University Expertise on Families and Life Span Transitions
University Expertise on Housing
University Expertise on Technology
General Administrative Unit on Staff Development and Training for Working with Persons with Disabilities
Community Program
Community Program
Community Program
Community Program
Department of Mental Health and Developmental Disabilities
Department of Rehabilitation Services
Department of Public Aid
Department of Public Health
Department of Children and Family Services
Division of Services for Crippled Children
Department on Aging
State Board of Education
Bureau of the Budget
Protection and Advocacy
Guardianship and Advocacy

Figure 1. Configuration for an inservice coordinated and unified staff development and training system for state agencies and local organizations providing services to persons with disabilities

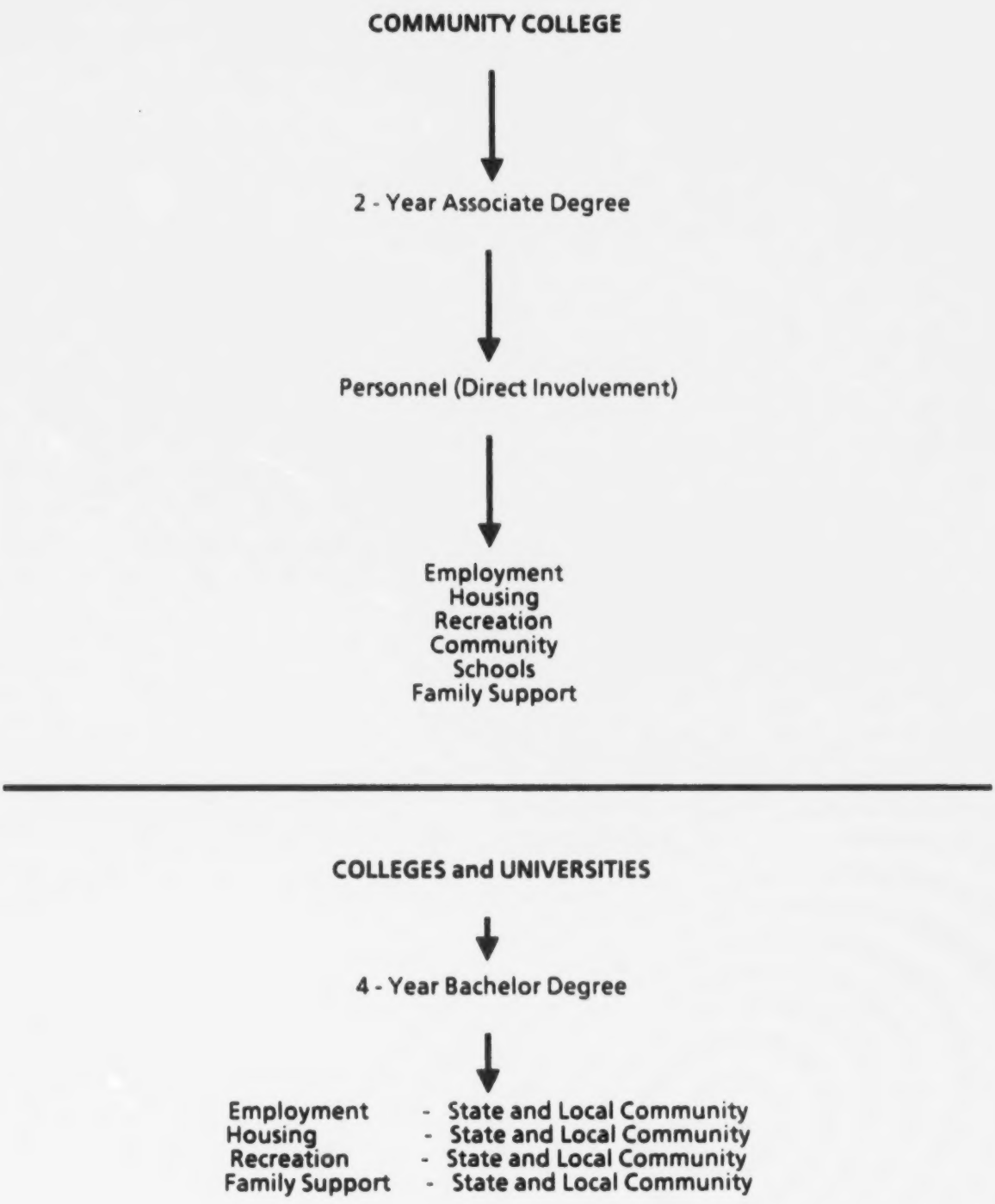


Figure 2. Configuration for a preservice model in two-year community colleges and four-year colleges and universities preparing personnel to work in local and state agencies supporting persons with disabilities.

**ISSUE: A BASIS FOR THE DEVELOPMENT OF A COMMON INTERAGENCY LIFE-SPAN CASE COORDINATION SYSTEM.**

I. VISION

A comprehensive case coordination system will exist which provides professional assistance in locating and securing needed services and benefits for persons with disabilities and their families. This includes coordination and monitoring of those services, for as long as they are needed.

II. ISSUE DEFINITION

At present, there is no comprehensive case coordination system serving people with disabilities in Illinois. A number of state agencies provide or purchase elements of case coordination, such as assessments, service planning, service monitoring, and advocacy, but each of these systems is limited in some significant way. Despite the funds spent on these systems, numerous people who require case coordination services do not receive them. Further, the existence of numerous case coordination services diffuses responsibility for providing needed assistance, is confusing to consumers and presents the possibility for duplication of services. This situation does not adequately serve people who need services and does not represent optimal use of state funds. What is needed is a comprehensive system which will eliminate these concerns by providing high quality, professional services to people with disabilities.

III. BACKGROUND

History: Case coordination has been an important element of human service systems in the last two decades. The federal Developmental Disabilities Act has contained requirements for case coordination since 1978. State law (Ill. Rev. Stat. Ch. 91 1/2, par. 100-53) has required case coordination services for persons with developmental disabilities since 1983. Public Act 86-921 (House Bill 69) requires that case coordination services be part of a service system plan. Case coordination is an allowable service under the state Medicaid plan, as well as under various Medicaid waiver programs. Case coordination requirements are also present in federal laws governing public health services.

Funding: Grants and contracts to community agencies funded by the Department of Mental Health and Developmental Disabilities (DMHDD), Department of Alcoholism and Substance Abuse (DASA), Department of Public Health (DPH), Department on Aging (DOA), Department of Public Aid (DPA) and Department of Children and Family Services (DCFS) for case coordination services totalled an estimated $ 39,000,000 for FY 1990. The amount expended by state

agencies for case coordination provided by their own personnel is more difficult to estimate, since these functions are provided by persons with many job titles, who devote varying proportions of their time to case coordination activities. Assuming that one-third of the time of professional staff working with agency clients is devoted to case coordination activities, an estimated $17,000,000 was spent in FY 1990 on these services. This gives an overall estimate of $ 56,000,000 in case coordination spending each year.

## IV. ISSUE ANALYSIS

The various statutory requirements cited above have resulted in the emergence of a number of distinct case coordination systems, each affecting people with disabilities in some capacity. However, the creation of a truly comprehensive system has not materialized. While a large amount of money is spent on case coordination, the limited nature of current systems means that funds are not spent efficiently.

Existing case coordination systems are limited in various ways. Some provide services of limited intensity or duration. Others serve only persons of certain age groups or specific disabilities. Some serve people only as long as they are associated with their specific agency or program. These systems view the person categorically--by disability, by age, by program need--rather than viewing the person holistically.

These case coordination entities do not consistently meet the essential needs of people with disabilities and their families in dealing with the human service system. The human service system has often been likened to a maze which must be traversed by the person seeking services. The number of service agencies and programs, and the various eligibility criteria and funding sources all present the potential for confusion for people already under stress. People need help in identifying services, establishing their eligibility for services and benefits, obtaining appropriate assessments and evaluations, developing service plans, coordinating the delivery of service in a manner acceptable to the person, monitoring the appropriateness of the services over time, and in advocating on the person's behalf within the service system. Further, such assistance should be provided by trained professionals who act solely in the interest of the individual with a disability.

Expansion of existing case coordination services is not the answer. The inherent limitations of these systems and the lack of cooperation and coordination among state agencies suggests that expansion will only create more confusion and not resolve the conflicts.

## V. PROPOSED NEW MODEL

Basic Requirements: All people with disabilities must be eligible to receive comprehensive case coordination services. Eligibility for these services will be based solely on the presence of a disability and not on the individual's status as a recipient. In other words, people would remain eligible for case coordination services regardless of what specific services they may receive from one or more state agencies.

Eligibility for case coordination services must not be limited based on the age of the person. Children and adults must be eligible so that continuity of services and supports can be provided even as individuals make transitions between other, age-specific service systems. Further, persons must be eligible regardless of the type or degree of their disability.

Proposed Structure: A system of independent, not-for-profit case coordination agencies should be established throughout Illinois to serve people with disabilities. These agencies would receive state funds and be subject to state regulations, but would be governed by independent boards of directors. Funding would be based on annual estimates of demand, and would ensure realistic caseloads. The agencies would be required to meet state standards for service provision and for staff qualifications. Some agencies of this type exist presently in Illinois, although the scope of their services is limited.

This system will make available to all people with disabilities the specialized assistance necessary to locate and obtain needed services. Case coordination staff will be able to act solely in the interests of the people they serve, without ties to any service providing entity. Services will be available as a person changes service agencies and as transitions are made between service systems.

The system should be administered by a board or commission appointed by the Governor. The commission would provide funding, set policies, establish regulations, and provide leadership for the case coordination agencies.

## VI. RECOMMENDATIONS FOR NEXT STEPS

The establishment of a new system will take some time. The following steps are recommended to improve case coordination services during the interim.

1. Existing case coordination providers must receive training to ensure interagency cooperation. A common training program must be developed which emphasizes values and principles that affirm the worth of people with disabilities and their families, focused on the rights of individuals, and which orients those being trained to

assist people in their efforts towards self-advocacy.

2. A multi-agency memorandum of agreement must be developed which describes a method for eliminating any duplication of service, and for providing individuals and families with consistency and continuity of services. When several agencies are involved on behalf of an individual, one professional must be designated as the primary case coordinator in order to achieve these goals.

3. Convene a group of representatives from state agencies, community organizations and consumers and their families to accomplish two tasks:

   a. Develop standards for case coordination which would define, at a minimum, scope, program expectations and personnel qualifications.

   b. Design the structure to accommodate the new case coordination system stressing the utilization of independent, not-for-profit entities. Additionally, strategies for the implementation of this new structure will also be recommended.

4. Obtain appropriation from the legislature for funding this case coordination system.

**ISSUE: A BASIS FOR THE DEVELOPMENT OF STATE OFFICE COMPLEXES AT THE COMMUNITY LEVEL TO FACILITATE 'ONE STOP SHOPPING.'**

I. VISION

Illinois will have a single point of entry into state services for all persons with disabilities. This point of entry will assure that individual consumer needs are effectively addressed through a comprehensive array of services and supports, including but not limited to: intake, assessment, linkage and plan development. Delivery of these services and supports will be addressed in a holistic and responsive manner. Endemic in this system is the recognition that each person with a disability would be empowered, positively supported and actively involved in developing a plan to meet mutually agreed upon life objectives. This process will be active, time efficient, integrated and monitored. State-of-the-art technology will be utilized to assist the consumer, state agency personnel and community providers in maximizing information assimilation. Relevant data regarding the individual's present and future needs will be stored in a central state data base system and will become integral to the state's strategic planning and financial allocations process.

II. BACKGROUND

Currently, the State Departments of Mental Health and Developmental Disabilities (DMHDD), Bureau of the Budget, Aging (DOA), Children and Family Services (DCFS), Public Aid (DPA), Public Health (DPH), Rehabilitation Services (DORS), Division of Services for Crippled Children (DSCC), Guardianship and Advocacy (G & A), Protection and Advocacy (P & A) and Illinois State Board of Education (ISBE) are the primary departments through which funding is allocated to serve people with disabilities within the State. At present, these departments have developed systems of service delivery which are not consistently interdependent and do not interact synergistically. Different intake, evaluation and eligibility criteria across State agencies offers the consumer a seemingly insurmountable challenge to successfully access the system.

In 1986, the Illinois Planning Council on Developmental Disabilities conducted a Unification of Services Study. The focus of this study was to examine the possibility of creating a separate Department of Developmental Disabilities and facilitate service unification for people with developmental disabilities, statewide. Functionally, this process implied that the Department of Developmental Disabilities (DDD) would be empowered to execute a controlling influence over services for persons with

developmental disabilities regardless of which state agencies provided those services. Conclusions of the study highlight eight major points (Attachment A) and clearly identify the need for Illinois to reorganize the service system so that citizens with disabilities are able to gain access to services throughout the State. DMHDD has a statutory responsibility for operating a case coordination system for persons with developmental disabilities. The Unification of Service study stressed, relative to case coordination, that even with an expanded case management system, coordination problems will still exist as long as there is no single entity providing services to persons with disabilities.

Some of the conclusions cited in the Unification of Services Study are still germane. A competitive model of human service delivery is endemic to Illinois' service delivery system. Limited planning and lack of interagency collaboration have been contributing factors. Within this competitive model, turf issues and myopic planning have isolated state agencies from providers. Additionally, this environment has not been conducive to fostering the development of cooperative and effective interagency relationships.

The Life Services System (LSS) of Ottawa County, Michigan has developed a mechanism for providing coordinated service planning for persons with disabilities who require services from multiple agencies. LSS facilitates the development and maintenance of relationships and defines responsibilities among existing human service agencies in Ottawa County to bring about greater effectiveness in the delivery of services.

During the three years, from June 1983 to June 1986, the major community agencies within Ottawa County, Michigan, had the unique opportunity, under a grant funded by the Michigan Developmental Disabilities Council, to develop and implement a cooperative services model. This pilot was extremely successful, and LSS became a system used by all participating agencies. In 1987, two additional agencies joined the consortium, Ottawa County Community Education Association and Ottawa County Employment and Training/Job Training Partnership Act.

The establishment of LSS allowed the community agencies within Ottawa County to successfully address the challenges frequently encountered when multiple agencies must work together. They include: issues of coordination, case management, communication, unity of purpose, and service continuity. Additionally, the solid linkages developed through the LSS model provided an excellent means to address gaps in the service system.

The Life Services System office provides a single point of

intake and coordination for all activities including assessment and service planning. Through this holistic approach, the Life Services System, is able to provide a comprehensive array of county-wide services developed to meet the individual needs of each client.

In 1988, Michigan's Governor Blanchard authorized the development of the Human Investment System which provides a single point of entry into the service system. Once it becomes fully operational, it will provide the general public access to information concerning education and job training.

As part of the integrated education and employment program, the development of a SMART card has been initiated. The SMART card is a mechanism designed to condense an individual's personal records onto a plastic card that presently has a 4K capacity. Plans to expand the capacity to 16K will enable any state agency to access a person's personal records, identify eligibility criteria across any state service system and monitor changes in eligibility information and services provided at any given time. The application of this technology in the State of Illinois to facilitate single point of entry services is worthy of examination.

## III. ISSUE ANALYSIS

Presently, within the state of Illinois, people with disabilities encounter a wide array of barriers inhibiting them from securing the services to which they are entitled. Within our current statewide service delivery system, limited cooperative interagency planning exists which integrates services across all state agencies serving individuals with disabilities. Lack of information regarding the services provided by various state agencies, inconsistent eligibility criteria, different and divergent planning areas across all state agencies and excessive rules and regulations preclude a prompt and responsive service delivery system for people with disabilities.

On the local level, agencies providing services for people with disabilities perceive one another as competitors. This competition breeds isolation, increases fear and mistrust and limits strategic interagency planning and cooperation. Individual state agencies fund a multitude of community service providers who provide duplicate services within the same geographic area. Consequently, service gaps may evolve due to the lack of local, regional and comprehensive state planning.

Presently, eleven state agencies facilitate services which impact people with disabilities within the State of Illinois. Today, the consumer continues to experience extreme

difficulty accessing coordinated services across multiple state agencies because the present system operates in a competitive rather than cooperative service model.

## IV. PROPOSED NEW MODEL

Integral to the new service model will be a single point of entry that will enable persons with disabilities to easily access the service system and obtain needed services. The systemic changes required in manifesting this conversion must reflect the successful applications pioneered in the development of the Life Services System of Ottawa County, Michigan. As with the Life Services System model, the Illinois system must provide intake, coordination, assessment, linkage and individualized plan development. Utilization of state-of-the-art technology similar to the Smart Card application must be considered integral to this conversion in order to complement the system. Additionally, this holistic approach will assure interagency cooperation and planning, thus providing a comprehensive array of services that meet the individual needs of the person seeking services. The opportunity to explore the efficacy of this proposed conversion is timely. Obviously the success of this model is highly dependent upon interagency cooperation.

## VI. RECOMMENDATION FOR NEXT STEPS

1. Obtain a governmental mandate to convene a task force charged with developing a strategy for conversion of the current system to one characterized by a single point of access. Special consideration must be given to rural, suburban and urban applications.

2. A study should be conducted to determine the feasibility and cost effectiveness of establishing regional, county or community level office complexes which would combine state agency offices.

3. Determine the feasibility of utilizing new technology like that of the SMART card being developed in Michigan to assimilate consumer information, establish eligibility and provide referral LINKAGE, thus integrating services across multiple state agencies.

4. Develop a strategy that assures the application of universal eligibility criteria across all state agencies.

## Attachment A

## Unification of Services Study

## Conclusions

This study examined a wide range of issues related to the potential establishment of an independent, cabinet-level state Department of Developmental Disabilities. At the outset it was stated that there was no correct answer regarding the proper method of organization for state services. However, the data collected provides information for all persons interested in shaping the decision to be made regarding creating a new department.

1. The amount of state resources devoted to services for persons with developmental disabilities is quite large, especially when services provided by agencies other than DMHDD are taken into account. Illinois has not neglected its citizens with developmental disabilities, although many persons are dissatisfied with the level of effort and financial support the state provides. The rate of growth in state spending for these services is extremely high, both in actual and inflation-adjusted dollars. That this rate of increase is not among the highest in the nation does not mean that credit should not be given for what has taken place in the last decade.

2. Illinois is not a leader nationally in services for persons with developmental disabilities. Illinois' rankings on various variables indicating commitment to DD services range from the middle to the bottom of the list of states. The movement toward small, community residential facilities that took place in other states never has received the same push in Illinois. Both the state and private providers tend to provide institutional housing, with over 9,000 persons with developmental disabilities living in large ICFDD's operated by all providers. At the same time only around 2,300 people live in community facilities with 12 or fewer beds. Per capita spending for DD services ranks only 30th nationally, a figure which is consistent with our middle ranking in terms of overall taxation, but which is perhaps inconsistent with our status as the state with the 10th highest per capita income in the nation.

3. There is overwhelming support from service providers and consumers for establishment of a separate department for services to persons with developmental disabilities. Consumers feel that a new department would provide a single source to turn to when services are needed, and eliminate the "runaround" so many of them encounter when contacting state agencies. Providers feel that such a

department could help them in dealing with what are seen as bureaucratic nightmares brought on by the involvement of numerous state agencies.

4. States which have cabinet-level departments of developmental disabilities have higher per capita spending on DD services, have higher rates of deinstitutionalization and spent a larger share of their DD services dollars on community services. One does not need a cabinet-level department to provide high quality services, of course. Michigan, which leads the nation in community services and deinstitutionalization, has the same model of organization as Illinois.

5. Establishment of a separate department in other states has proven somewhat costly in the first year or two, but over a period of several years the rate of growth in spending for DD services was no different from the national average. In other words, there is no evidence that establishing a separate department is more costly in the long term.

6. The demand by Illinois consumers for consolidation of <u>responsibility</u> for services for persons with developmental disabilities must be met by the state. This issue transcends the question of establishment of a separate cabinet-level department. Illinois citizens with developmental disabilities <u>must</u> be able to gain access to services through the state, and the various departments of state government must not be able to refer them away when they request services. DMHDD has the statutory responsibility for operating a case coordination system for persons with developmental disabilities. This system needs to be strengthened so that all persons will be able to acquire the services they need. Whatever the structure of the system, this component must be at the core.

7. Illinois law makes the establishment of a Department of Developmental Disabilities a relatively simple matter. The Executive Reorganization Implementation Act allows for the creation of departments by executive order providing that the legislature does not object. New agencies can assume powers of existing agencies and the statutory changes can be worked out later. This makes the transference of primary responsibility for DD services from DMHDD to DDD relatively easy to accomplish. Many practical details would need to be worked out, presumably over a transition period.

8. While creation of a new department is easy, the transfer to that department of administrative responsibility for programs which carry a federal requirement for "sole agency" administration is not simple. If DDD were to be

created, it would be advisable to begin developing creative options for joint administration of Medicaid, Vocational Rehabilitation and perhaps even Special Education programs, even though DPA, DORS and ISBE are empowered as sole administrators of the federal funds used in those programs. If it is desirable to have a comprehensive reorganization of DD services, then such creative solutions should be found. If not, DDD would be no more than the removal of the DD Division from DMHDD.

**ISSUE: A BASIS FOR THE DEVELOPMENT OF SIGNIFICANT LEGISLATION TO IMPLEMENT THE INTERAGENCY STRATEGIC PLAN AND OTHER INTERAGENCY RELATIONSHIPS.**

## I. VISION

The development of significant legislation is critical in order to effectively implement the Interagency Strategic Plan for Illinois Citizens with Disabilities. Such a coordinated approach to legislative initiatives will enable Illinois citizens with disabilities to fulfill their visions to be productive and have the opportunities to exercise the same rights, responsibilities, and opportunities to achieve personal goals through participation in the community. A common value base in government should guide the principles, policies, plans, and legislative advocacy that will contribute to the realization of this vision. The enactment of laws, legislative findings, and resolutions represent a means to ensure services and supports, ensure the most effective utilization of resources, and create a mechanism for public and private sector coordination and cooperation.

## II. ISSUE DEFINITION

The development of significant legislation to implement the Interagency Strategic Plan or to otherwise coordinate a fragmented service system has not occurred in the State. The ineffectiveness of the current system combined with the perpetual competition for available resources has fostered a disjointed approach to major legislative initiatives and the related promulgation and enforcement of associated regulations.

The current system of multi-agency responsibility for service delivery results in defacto segregation of services received or not received to meet an individual's entire needs. The lack of an entitlement to services and supports, and equally important, the non-aggressive enforcement of the regulatory environment will continue the status quo.

## III. BACKGROUND

There is evidence of a shift at the federal and state level in terms of values and principles that shape how and what services or supports are offered to persons with disabilities and their families. A critical consideration for Illinois is the actualization of a common set of values and principles established through planning and subsequent legislation.

One of the more coordinated and cohesive efforts on major legislative and reform initiatives was the original Governor's Commission for Revision of the Mental Health Code of Illinois. This blue-ribbon panel was comprised of governmental and non-governmental representatives throughout the State. National organizations such as the President's Committee on Mental Retardation and the Mental Health Law Project (1976) assisted the commission in developing a package of major statutory reform legislation to the civil and criminal laws of the state of Illinois.

Twelve years later in 1989, the Commission to Revise the Mental Health Code reiterated the findings of the earlier Commission. Specifically, the 1989 Commission found that Illinois is one of the few states that had failed to develop a comprehensive unified system for providing care to its citizens with mental illness and developmental disabilities or in making adequate provision for community care. This Commission again urged "...that such a structure be developed and that Illinois create a mandate for community care."

During the intervening twelve years the state has seen the introduction and passage of several legislative proposals introduced by various state agencies that fix pieces of the system or have called for additional studies or needs assessment on various aspects of the service system. This fragmented and uncoordinated approach has reinforced the continuum model of service delivery.

The Developmental Disabilities Services Law, or House Bill (HB) 69, was originally intended to be an entitlement bill guaranteeing people access to services and supports. However, given the opposition by some state agencies, a compromise was reached in order to assure support and passage of the bill. HB 69, as passed by the legislature and signed by the Governor, called for the development of a Developmental Disabilities Services Implementation Plan; no entitlement to services was established under the Act. The Illinois Planning Council on Developmental Disabilities is required under the Act to submit a report to the General Assembly by November 15, 1990 that may include a proposal for legislation to implement any of the services specified in the Plan.

## IV. ISSUE ANALYSIS

Legislative initiatives intended to influence the appropriations process range from seeking technical changes in existing statutes to achieving significant program expansion or developing new programs. Each year, individual state agencies independently introduce a number of bills.

Generally, each agency seeks and obtains some level of support from advocacy organizations, other state agencies, key lobbyists, legislative leaders and the Office of the Governor. Agency-initiated legislation tends to focus upon offering solutions to problems of an implementation or maintenance nature or issue specific remediation.

Currently, there is no development of an annual interagency common legislative agenda. Program expansion and initiation of new programs do bear, at a minimum, an awareness of legislative initiatives at a coordinated level. An interagency task force or legislative team would provide such coordination. This would be similar to the efforts of the HB 69 Advisory Committee. The development of an interagency task force must have the support of the Administration, key legislative leaders and the various state agencies.

## V. PROPOSED NEW MODEL

Effecting system-wide change in the implementation of a philosophy that promotes the independence, productivity and integration of persons with disabilities requires a level of interagency and special interest group coordination and oversight on legislative proposals.

Establishment of a interagency legislative team to develop significant legislation to implement the Interagency Strategic Plan would assure increased coordination, maximization of effort and reduce current duplicative activities. The interagency team would be comprised of staff from the Governor's Office of Legislation, consumers and their families, community provider organizations, and legislative staff representing the following state agencies: Department of Mental Health and Developmental Disabilities, Department of Rehabilitation Services, Department of Public Aid, Department of Public Health, Department of Children and Family Services, Division of Services for Crippled Children, Department on Aging, State Board of Education, Bureau of the Budget, Protection and Advocacy and Guardianship and Advocacy.

## VI. RECOMMENDATIONS FOR NEXT STEPS

1. Obtain a governmental mandate to develop an interagency legislative team to coordinate legislative activities pursuant to the Interagency Strategic Plan. Responsibilities of this team would minimally include:

    a. Conducting a discrepancy analysis of state agency mandates, powers and duties, and performing a regulatory review of rule promulgation and enforcement.

b. Developing an annual legislative agenda for significant legislation to implement the Interagency Strategic Plan.

## CONCLUSION

The issues addressed in The Common Pursuit have been explored in concert with the recommendations formulated by the H.B. 69 Advisory Committee. Although this document reflects the culmination of many months of dedicated work by many individuals, the Council recognizes that it is only a first step in the succession of many which must now follow.

The first step, however, represents a critical one because it ensured persons with disabilities a strong voice in establishing the future visions embodied in The Common Pursuit. Additionally, it will facilitate informed decision-making relative to prioritizing the issues addressed in the document. This prioritization process will be instrumental in the development of an interagency strategic plan which the Council is determined will address not only the letter but also the spirit of the H.B. 69 legislative mandate; to improve the service systems supporting Illinois citizens with disabilities.

During these times of diminishing federal funds and a constricted state budget, the Council recognizes the critical necessity to maximize the impact of existing generic and specialized resources through effective interagency collaboration and cooperation. Because of its dynamic value-driven qualities, a coordinated interagency strategic plan is an efficacious method to achieve this outcome.

The Illinois Planning Council on Developmental Disabilities extends its sincerest gratitude to the many persons with disabilities and their families, advocates, service providers and other professionals who contributed to this process. The tremendous assistance provided by each of these individuals in developing The Common Pursuit has been invaluable and represents a critical step in manifesting a vision which ensures that Illinois citizens with disabilities will freely enjoy the same opportunities and benefits enjoyed by citizens without disabilities. The spirit of those simple, yet elegant, values embraced by our nation's Declaration of Independence must ring clear for **all** people.

> **'We hold these truths to be self evident, that all (persons) are created equal and endowed with certain unalienable rights, that among them are life, liberty, and the pursuit of happiness.'**

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